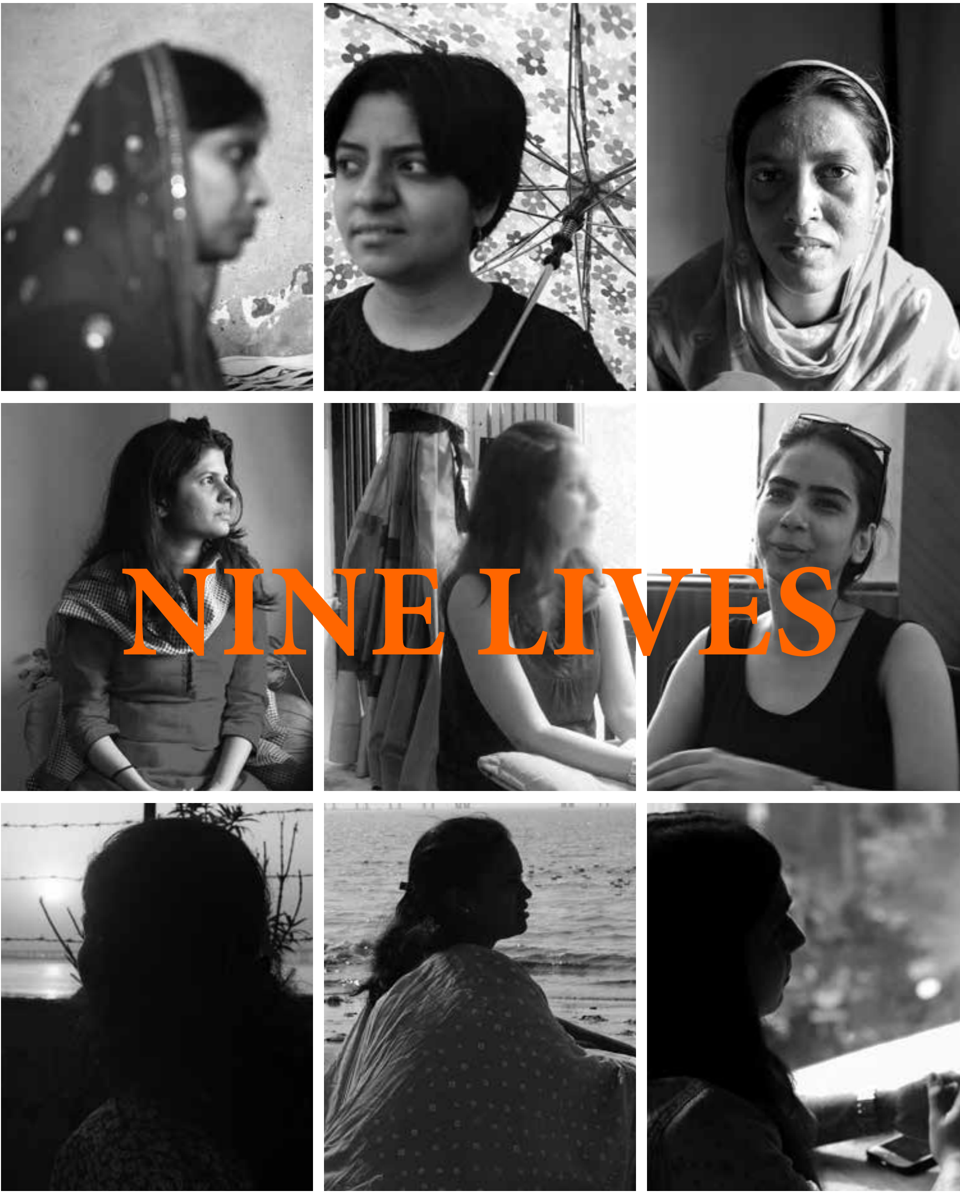
NINE LIVES



Cover and book design by Facet Design

The story of Nurjahan has been used with kind permission from Lilly MDR TB Foundation.

About this collection: The documentation of this collection was conceptualised by Chapal Mehra. The story documentation was led by Zarah Udwadia and Chapal Mehra.

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Note: Some identifying details have been changed to protect the privacy of individuals. All details presented in the stories are as narrated to the authors and have been presented with utmost accuracy. All stories in this collection have been documented and published with written consent from the individuals

Cover Picture by: Shampa Kabi

SURVIVORS Against TB
pi CONSULTING

CONTENTS

AUTHOR'S NOTE

Nearly three years ago, in a narrow crowded by-lane in Dharavi, a woman told us her tale of surviving Tuberculosis (TB). Of spending hopeless months going from one doctor to another, of spending thousands of rupees, of being abandoned by her husband, until she was finally diagnosed with a highly drug-resistant form of TB - it took several years for her to be cured and to reconstruct her life. She still lives in Dharavi, fearful of even a cough around her.

Her story is not in this collection, but she did inspire this volume. In India, as also elsewhere, women always bear the burden of diseases like TB more severely. A woman affected by TB in India often suffers silently, with little hope in a system and society which treats them no different from their male counterparts, not seeing the extra burdens and restrictions they live under. Beyond the physical suffering, TB has enormous mental, social, and economic consequences for women that remain ignored.

When we began documenting these stories, we wanted to record the lived journeys of women surviving TB in a patriarchal society where they often have limited access to health services and little agency to negotiate their own well-being. They live with stigma, fear and discrimination when infected with TB. Even when cured, they are told never to talk of TB again, as if it were somehow their failing, their fault.

As you read these remarkable stories filled with grit, determination and courage, we hope you understand the numerous challenges that these women and their families have faced to defeat TB. It is for these reasons that we have ended this volume with a set of recommendations that have been put together with inputs from female survivors, experts and program planners. Our intention in doing so is to provide a roadmap to make TB services and the health system more responsive to gender specific needs. We also hope that these stories will spur decision makers to act on these recommendations. In the end, we must recognize that the way women experience, live and fight TB or any other disease is different, and our society and health system needs to respond to them more sensitively.

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ACKNOWLEDGEMENTS

This volume would not have been possible without contributions and support from Zarir Udwadia, Sunita Prasad, Vikas Panthiba and Shashank Ganatra among others.

The photographs in this volume have been clicked by various photographers. Given below are their details:

1. Durgawati –Rohit Saha
2. Nandita –Rohit Saha
3. Nurjahan –Rohit Saha
4. Deepti –Rohit Saha
5. Debashree –Rohit Saha
6. Manasi –Shampa Kabi
7. Sarika –Prachi Gupta
8. Tejal –Manasi Khade
9. Saher –A Sreedharan

We are extremely grateful to them for their contribution to this volume. They worked under extremely challenging situations and made pertinent representations of our subjects.

Finally, we owe the female survivors included in this volume a significant debt. It was with deep courage, honesty and clarity that they shared their stories with us and took us into their homes and lives. We left as close friends and collaborators. We hope that our writing does justice to their stories.

INTRODUCTION

Tuberculosis or TB is India's severest health crisis. It kills almost 1,400 Indians every day or one Indian every minute. However, its impact on and risks to the health of women and children is often neglected. TB kills more women in India than all other causes of maternal mortality combined. Yet, we rarely view this crisis as a gendered one.

TB's impact on women and children is far wider than its clinical manifestations. It is estimated that more than 1,00,000 women lose their status as mothers and wives because of TB-related stigma. A study done by National Institute of Research in Tuberculosis (NIRT), Chennai revealed that 11% of children drop out of school on account of parental illnesses and 20% of children have to take up jobs to support families because their parents had TB. It is estimated that more than 3,00,000 children may have left school permanently because of their parents' TB.

This publication brings together the stories of several female survivors of TB. Why is this important? Because they chronicle the journey of these brave women in a deeply patriarchal society, where they face stigma, sometimes coupled with poor socio-economic status, and lack of awareness that leads to significant delays in the diagnosis and treatment of TB. Yet they persist in their fight against TB.

What do these stories tell us? That women have to fight harder to defeat TB even though families, communities and often the health system abandons them. A study in Mumbai revealed that married women tried, often unsuccessfully, to hide their disease for fear of desertion, rejection or blame for bringing the disease. Women dropped out from treatment because of the pressure of housework, and the stress of keeping their condition secret, particularly when their movements outside the home were routinely questioned. Also, with little access to stable income or social support, when women lose their partners to TB, families often abandon them.

As TB is airborne, everyone is exposed to it and about half the adult population in India has some evidence of latent or dormant infection. So, what activates the latent bacteria to multiply and produce symptoms only in some people, while the majority are able to contain it? The most important risk factor in India is under-nutrition – it has been estimated that at the population level, under-nutrition accounts for over half of all TB cases. This association is even stronger in the case of women and marginalized communities, like scheduled castes and tribes. While smoking and alcohol addiction are additional risk factors in men, in the case of women, it is exposure to indoor air pollution. In rural areas, many women still cook indoors in poorly ventilated spaces using biomass fuels and are more likely to develop not only TB but also chronic lung diseases. Young children who stay with their mothers are also exposed to this risk.

We must begin by mobilizing political commitment and resources to assure gender-equitable access, including women and child-friendly services.

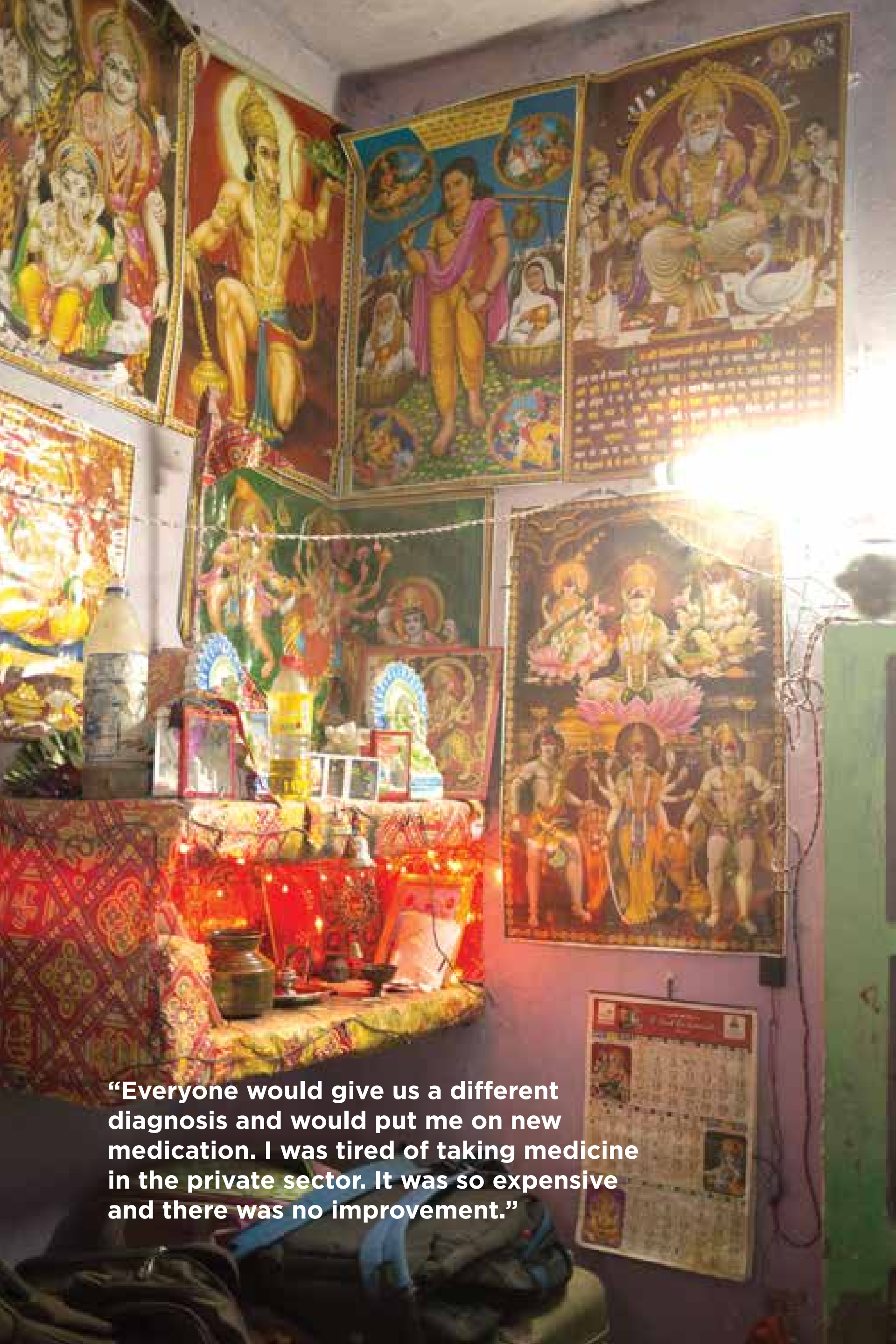
We also need to create synergies across the health system. Its time we made health programmes sensitive to the constraints faced by women and children in accessing care or completing treatment.

We also need to create specific campaigns focused around women and children to sensitize communities on TB. We need to make clinics more gender-friendly and sensitive to patient's needs. Improving the nutritional status of women and children will help prevent TB, while those with the disease may need additional nutritional supplementation. We also need to invest significantly in development of new tools, including shorter treatment regimens and child-friendly diagnostics and medicines.

I am delighted to introduce this publication not only because it is a timely reminder of the challenges women face when they encounter diseases like TB but also because, cutting across party lines and political beliefs, we need to come together to empower our women to fight TB.

When you read this publication you should not forget that this could be anyone's story. And there are thousands of such stories. What will they teach us? That a developed India is not a possibility until we make our women free of diseases like TB. This is more than an issue of concern; it is a call to action for those in power, especially women, to join forces to create an India where women are able to fight any disease, not just TB, free from fear and stigma. Only then will India become the super power that it wishes to be. I urge those who read this publication to join forces and form a group which works within the corridors of power, as well as outside them, to ensure that TB is no longer a death sentence for women. Lets end TB in India!

Lalitha Kumarmangalam
Chairperson
National Commission for Women



> “Everyone would give us a different diagnosis and would put me on new medication. I was tired of taking medicine in the private sector. It was so expensive and there was no improvement.”

DURGAWATI

32, HOUSEWIFE, NEW DELHI

Durgawati sits in her room, surrounded by pictures and idols of Hindu gods and goddesses. On the wall near her bed is an altar crammed full with idols of various sizes, decorated with small twinkling electric lights. She recalls her fight against TB. Her father- and mother-in-law stand beside her, chipping in every now and then.

Durgawati survived TB twice. She was barely 20, and pregnant with her first child, the first time she was diagnosed. They were in her husband's ancestral village for her brother-in-law's wedding. Her in-laws sent her home to her father's house, where she received treatment through the private sector. She took TB medication for almost 9 months. "I got plenty of rest and care and I thought that was the end of it," she recalls. At that time, neither she nor her family knew that the government gave free TB medication. This is not surprising as most people affected with TB continue to be unaware of the government's TB program.

“We just wanted her to get well as quickly as possible so that she could be with her children,” her mother-in-law says. Cured of TB, life continued predictably for Durgawati. She gave birth to three more children and was a busy homemaker. In 2013, she started coughing again. The cough was accompanied by fever and chills that lasted for weeks. She went to the local hospital and to numerous doctors, yet no one gave her a clear diagnosis. “Everyone would give us a different diagnosis and would put me on new medication,” Durgawati remembers.

The family took her from one doctor to another, each of whom treated her for seasonal cough and chest infection. As a result, she would start treatment every 2 months and then stop. “I was tired of taking medicine in the private sector. It was so expensive and there was no improvement,” remembers an exhausted Durgawati.

Even though she presented all the classic TB symptoms, none of the doctors ever diagnosed her with it. Eventually, her family took her to Dr Sharma, a private doctor in Delhi, who diagnosed her with drug-sensitive TB. Finally, it seemed that the correct treatment began for her.

However, even after months of medication, there was no discernible improvement in her condition. In 2014, Sharma eventually sent her to the local DOTS centre, saying he could not treat her any further. There, she tested positive for multi-drug resistant (MDR) TB and was started on an MDR TB regimen.

The family crowd around and listen intently to Durgawati as she relates her story, reliving every moment of it with her. Along with her, Durgawati’s husband and her children were the most severely affected by the recurring misdiagnosis of TB. “It didn’t need to take this long for her to be cured. She is a classic case of misdiagnosis and incorrect treatment,” her health worker, a young woman who handles MDR TB cases, says softly.

Diagnosis was one challenge and treatment yet another. MDR medicines were hard to take and nothing prepared Durgawati for

“We just wanted her to get well as quickly as possible so that she could be with her children”

them. “I could barely do any work and my temper would often be out of control. I was even violent sometimes,” she whispers meekly. Her mother-in-law recalls that she would often lose her temper with her kids and sometimes raise her voice at her ageing in-laws. She was later told that this was a side-effect of cyclosirine, a medicine that often causes mood swings and hallucinations. Yet no one had counselled her or her family about what to expect and how to handle it.

Luckily for Durgawati, her brother in-law was a volunteer with a local TB non-profit and got her transferred so that she could be under their care. The health workers dealing with her there were more compassionate and there was also counselling for her and her family. “My DOTS provider was kind and explained to me how dangerous MDR TB was. She told me if I wanted to live I had to eat this medication. I never gave up on the medication,” she says.

During the two years of treatment, Durgawati needed constant care. She couldn’t eat anything and would often ask for iced water, as she felt her body was on fire. The toxic side-effects made life difficult for her and her family. She would sometimes not recognize her own kin, including her brother who came to visit her. She would often ask her own children who they were. The children remained understanding observers to their mother's battle with TB. During this time, her mother-in-law took care of the children.

At one point she became so unwell that her husband had to stop working to take care of her. During this period, the NGO that was treating her stepped in to provide nutritional support for 6 months. "I don't know how we would have survived without it," she says. Sufficient nutritious food is a critical requirement for those affected by MDR TB, especially those with limited economic means. This, however, remains out of reach for most patients who need it. Many eventually give up on medication altogether. Durgawati was lucky that the NGO was there to help her and her family.

Her biggest fear during the entire period was that she would infect others in the family. She would tie a handkerchief on her face all day. Considering the small home that they lived in, the NGO suggested TB tests for the members of the family; fortunately, all turned out to be negative.

For Durgawati, the severest impact of TB was not physical but emotional. As she recalls the time spent fighting TB, her frustration at being unable to fulfil her role as a mother and wife is overwhelming. "So much time passed when I ignored my children and my family due to this disease," she says. As her mother-in-law narrates how she and her husband took care of the 4 children, Durgawati agrees, nodding silently.

Despite the enormous physical and economic burden, the family never gave up on Durgawati's treatment. This is in contrast to the numerous cases where TB leads to abandonment or lack of support for completing treatment. Her husband's role was critical in this regard. "He never gave up on me," says Durgawati gently.

It's early evening when Durgawati's husband returns from work. A welder by profession, he left work for almost 6 months to take care of his wife. "We all took care of her," her mother-in-law insists, although her husband's contribution is clearly most significant. He narrates the entire period of 2 years in a matter-of-fact manner, correcting dates and details of Durgawati's fight with TB.

The family lives in a small house in a North Delhi slum, with one of the largest open waste dump yards in the city nearby. It rises like a minor peak, almost shrouding the nearby slums. The air is particularly terrible here, says the health worker. The houses in the slum are pukka, but lack ventilation. This is a virtual hot bed for transmission of TB. It's not surprising that the NGO treats a large number of cases, both for drug-sensitive and drug-resistant TB.

The family never hid Durgawati's disease from the community. The neighbours were understanding and sympathetic and would often inquire after her. The family faced no obvious discrimination. "In this small community, it would have been impossible to hide it anyway," her husband says.

The family feels no bitterness that Durgawati was misdiagnosed and they had to spend so much on her treatment. "We did everything that the doctor told us. We are grateful she got well and her TB is cured," says Durgawati's father-in-law. "We just want her to remain well," her husband says, looking at Durgawati.

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NANDITA

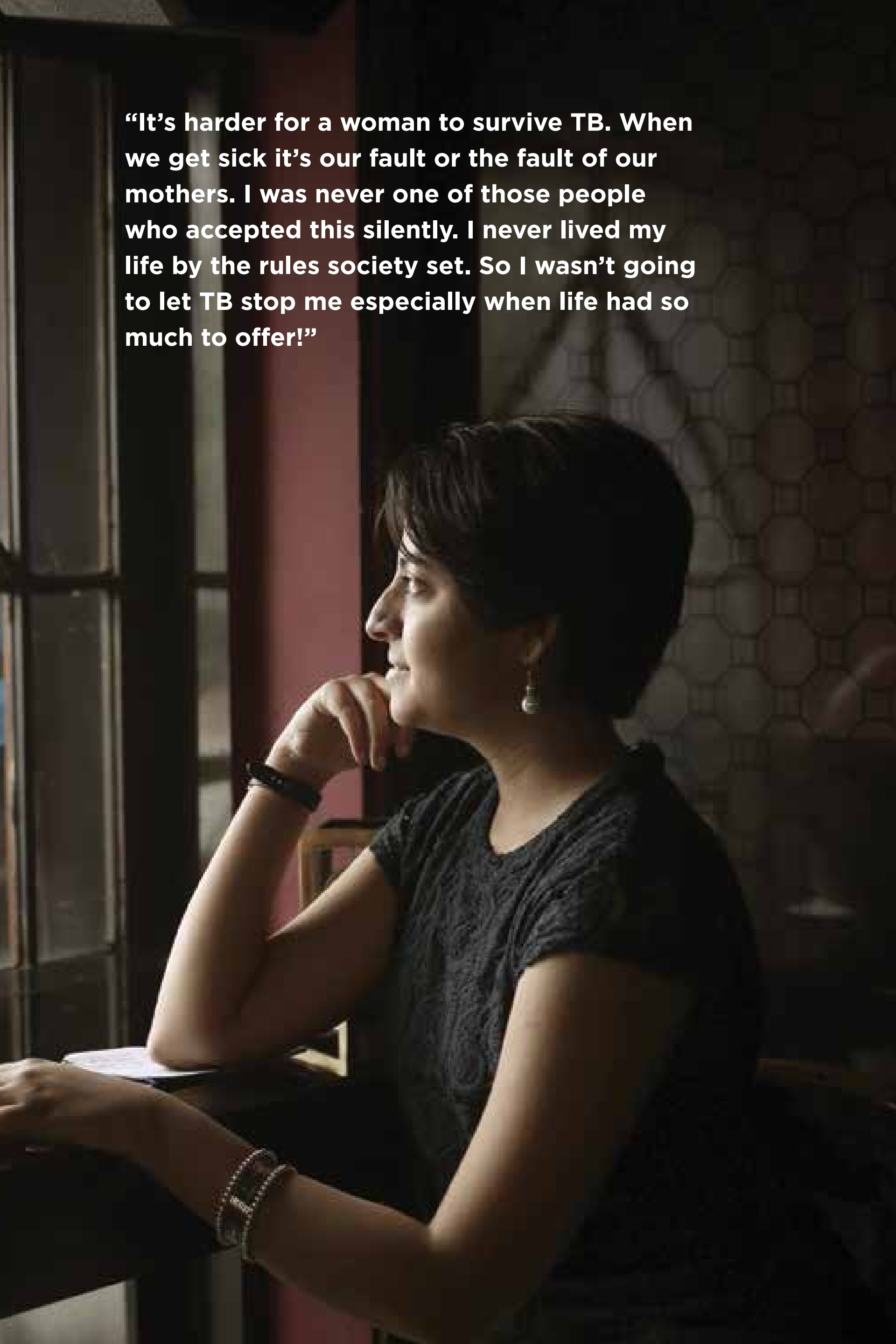
26, JOURNALIST, MUMBAI

"In India, or anywhere in the world, it harder for a woman to survive TB. When we get sick it's our fault or the fault of our mothers. I was never one of those people who accepted this silently. I never lived my life by the rules society set. So I wasn't going to let TB stop me especially when life had so much to offer," Nandita, barely 26, leaning by the crumbling wall of the Bandra Fort says this aloud as she recalls her struggle with TB. Behind her, the Mumbai sea glitters mutely in the fading evening light.

TB changed Nandita's life. She was 18 and had just begun college. She started having severe abdominal pain, accompanied by extreme nausea and a mysterious loss in appetite. "I was super excited about my college life and then this sickness began," she says animatedly.

The initial diagnosis was a viral infection because of the Mumbai rains. Though the rains ended, her sickness didn't. Every evening she would

“It’s harder for a woman to survive TB. When we get sick it’s our fault or the fault of our mothers. I was never one of those people who accepted this silently. I never lived my life by the rules society set. So I wasn’t going to let TB stop me especially when life had so much to offer!”



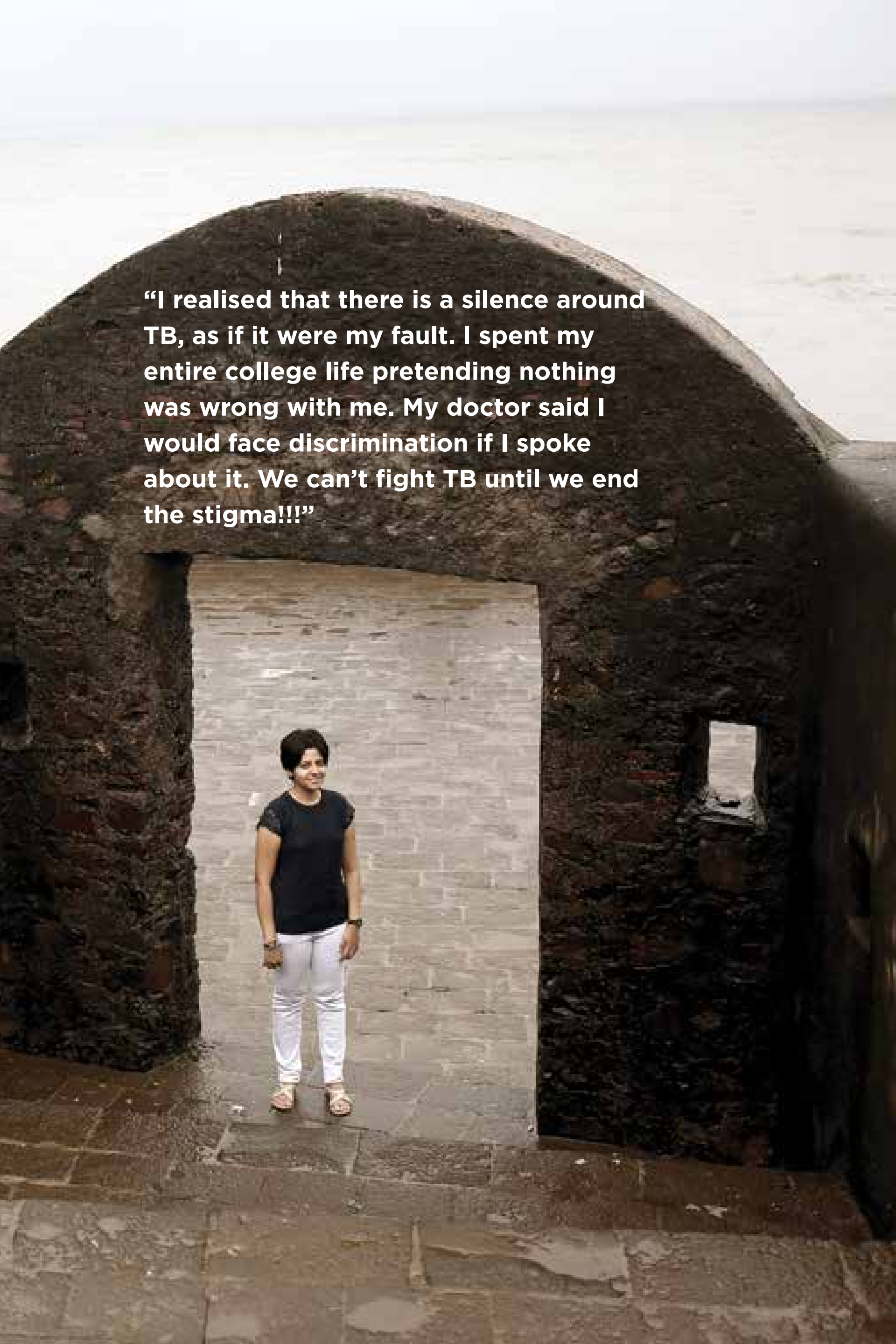
get very high fever and she would constantly feel exhausted. She was also barely eating anything. Despite a battery of tests, diagnosis became a challenge until she changed to a new doctor. “She was the first to suggest intestinal TB. No one else even suspected it,” she says.

A CT scan confirmed the family’s worst fears. “TB was just a medical term that we had heard. We knew no one who had survived TB or maybe no one spoke about it. And that too in the intestines?” The family’s surprise mirrors what most TB-affected families encounter when diagnosed with TB – horror and surprise at how little anyone in India talks about it. “I later learnt that even most doctors miss diagnosing extra-pulmonary TB,” Nandita says, reflecting on the irony.

The diagnosis came right in the middle of Nandita’s first-year exams; taking those exams with the pain and fever was terrible. The medicines began soon after. Even though Nandita was determined to fight TB, no one had counselled her on what to expect. “I was just 17, and the side-effects were terrible. I had severe nausea, mood swings, a constant sense of weakness and had to take leave from college.”

Looking out from an alcove in the Bandra Fort as rain begins to fall gently, she recalls the impact of being infected. “I was consuming close to 15 tablets a day. I had never felt lower in life. There was also terrible weight loss.” The issue, as with most TB-affected women, was deeper than the physical impact. “My doctors had told me not to mention TB to anyone. I realised that there is a silence around TB, as if it were my fault. I spent my entire college life pretending nothing was wrong with me. My doctor said I would face discrimination. This inability to talk about TB added to my frustration.” Not surprisingly, she was diagnosed with depression.

Her depression led to a lack of confidence. She avoided going out with college friends. They, too, were perplexed by her behaviour and took to taunting her about her social problems. “‘She really needs to grow up,’ they would say to my face. No one knew there was always a nagging



“I realised that there is a silence around TB, as if it were my fault. I spent my entire college life pretending nothing was wrong with me. My doctor said I would face discrimination if I spoke about it. We can’t fight TB until we end the stigma!!!”

feeling that you have to reach home on time so that you could eat those 15 tablets," she says wryly.

In 2009, Nandita was finally declared TB-free and her medicines were stopped. "I was given an assurance that TB would never return. It took me some time to get over TB. I decided to move to Delhi – a new city – to start afresh." Life finally seemed back on track. Nandita had a new career and new friends and was focussed on making the best out of it. In 2012, she moved back to Mumbai, because she wanted to study finance and build a career in financial journalism.

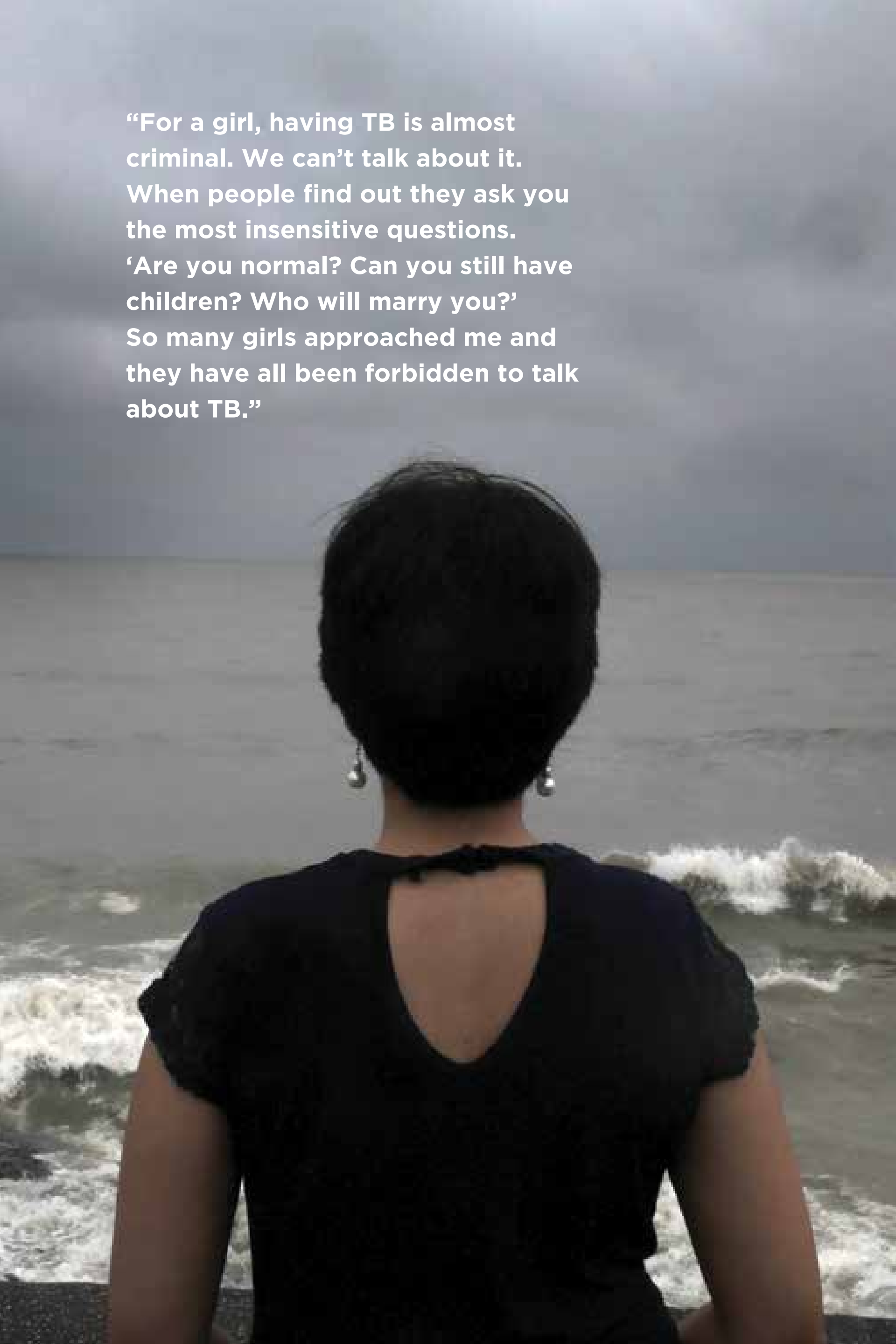
In 2013, she started getting a familiar pain in her lower abdomen again. She went back to her doctor who gave her viral medicines hoping, that it wasn't anything serious. But the pain only got worse.

"I still remember the day my doctor told me that it might be a reinfection of my intestinal TB. I was gripping my mother's hand under the table. I could not believe TB could return. Every single painful memory came flooding back. I felt defeated and lost." Her doctor told her she didn't know anyone who had a reinfection. But the words don't mean anything. "You are left wondering, 'Why me?'"

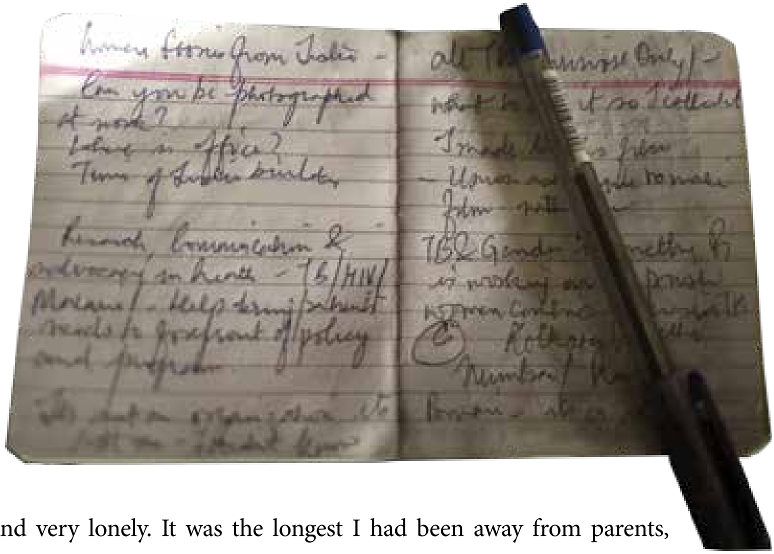
This time the TB was far more severe. The medicines did not make the pain subside. She was eventually asked to get a surgery done. "I dreaded hospitals, but here I was, being wheeled into an operation theatre on my father's birthday. Those 10 days after surgery, I hoped I would resume a life. You survive every trauma hoping that it has an end," she says.

This, however, was not the case. After surgery, Nandita developed an internal fever of about 105 degrees Fahrenheit. While getting her CT scan, she turned breathless and collapsed. Her intestines had got entangled, causing a near-fatal blockage. She draws a set of fuzzy intertwined tubes on a paper to explain it.

Nandita was in the hospital for close to 2 months; she had 3 life-saving surgeries, followed by 2 more later. She was admitted to the ICU and had to stay there for almost 10 days. "It was traumatizing and terrifying



“For a girl, having TB is almost criminal. We can’t talk about it. When people find out they ask you the most insensitive questions. ‘Are you normal? Can you still have children? Who will marry you?’ So many girls approached me and they have all been forbidden to talk about TB.”



and very lonely. It was the longest I had been away from parents, family and friends," she says, looking down at her hands.

"It was a cruel game. I remember lying in bed, thinking that there was so much more that I would want to do and perhaps would never be able to do. You see mortality and you think that if I survive I won't look back."

"Somewhere from within me came the resolve to fight back. I began researching on TB, asked my doctor lots of questions. Good doctors love proactive patients. My doctor shared everything with me that I wanted to know. It made me feel more secure," she recalls.

But for Nandita, the challenges were far from over. "I celebrated my birthday on 24th November and two days later, I lost my hearing. It was a side-effect of the medicine that I was on. I am a communications professional and I can't hear others," she says, smiling.

With time, Nandita got better and she turned to dance as a way of healing. It helped her channel her frustration into something creative and she has since given several performances.

"Society punishes a sick woman in every way that they it can. Some said that my moving to Delhi gave me the reinfection. Would you ever say this to a guy who made it to IIT Delhi – that his move gave him TB? The reason you can make this comment is because I am a girl. You will never ask a guy about who will marry him. Or whether he is normal!" she says emphatically.

While Nandita may have fought TB bravely, she knows it is difficult for other women. "For a girl, having TB is almost criminal. We can't talk about it. When people find out they ask you the most insensitive questions. 'Are you normal? Can you still have children? Who will marry you?' So many girls approached me and they have all been forbidden to talk about TB."

Surviving TB came at huge cost. The hospital bills forced the family into debt and they had to sell their home to move to a smaller rented apartment in a suburb further away. Her father's retirement savings and her own savings were consumed by her treatment. Nandita never went to seek treatment with the government. "I didn't know about

Had I known, I would have tried to go there. Revised National Tuberculosis Control Program (RNTCP). If I had I known I would have tried to go there. Why isn't there enough awareness? Why does the private sector charge so much for this disease?" Her questions reflect the concerns of numerous other TB patients.

"It's going to be hard to find a companion who would be understanding and supportive in a society such as this," she says, reflecting on marriage. "I am a single, independent woman and I can tell you the problems women face are quite different. We suffer far greater stigma. Today, we need programs that are specifically targeted at women. We need counselling for female patients and their families. We need to break this silence around TB in India, especially for women."

"It's not my fault I got TB, but it is to my credit I defeated it and built a new life. You can't end TB for women until you break the silence around it. Battling TB is not a tale of shame and disgust. "Be proud that you defeated this deadly disease," she says, as she walks out of the crumbling Fort and the rain descends torrentially on Mumbai, covering it in a warm embrace.

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NURJAHAN

28, HOUSEWIFE, KATWA

It's burning hot in Katwa as Nurjahan sits on the bed, gazing through the window at the dusty village road leading to her house. Her seven-year-old daughter, Nargis, sits beside her, leafing through her textbooks. A table fan blows directly onto them, a fervent but ineffective warrior against the heat. On the wall behind the bed is a cabinet filled with toys for Nargis.

Nurjahan, almost 29, is now in her last month of treatment for multi-drug resistant (MDR) TB. It all began in 2008. Nurjahan was taking care of her elder sister, who was an MDR TB patient being treated in New Delhi. Her sister passed away, as her diagnosis had been excessively delayed and she was unable to get appropriate treatment. After her death, Nurjahan returned to her parent's home in Kenda. Soon after, she started coughing and was diagnosed with drug-sensitive TB. She was put on DOTS treatment and pronounced cured after six months. In 2009, she married her sister's widower, who is also her aunt's son.

It's unclear why her TB returned, but in 2010, Nurjahan was coughing again. This time she went to a local doctor named Dr Liyaqat Ali in Katwa. He made her do several tests, including a blood test and an X-ray. He diagnosed her as having drug-sensitive TB again.

Having survived TB once, Nurjahan was cautious. She went to the Katwa government hospital and got herself a 'cough' test to confirm Dr Ali's diagnosis. The results left her devastated. "I thought six months of treatment was the end of TB. Nobody tells you it can happen again and again," she says. Unfortunately, none of the doctors tested her for drug-resistant TB.

Nurjahan has now been on treatment for almost four years for a disease that is usually cured within 6 to 24 months. She frequently looks out of the window by which she sits – sometimes all day – trying hard to recollect dates, but often mixing them up. "Nurjahan was given Category One drugs once, but given Category Two drugs twice, despite failing it the first time. Weren't you?" Rano, her counsellor, a relatively young but persuasive woman reminds her. Nurjahan nods vigorously.

Recognizing that Category One had failed, Nurjahan was started on Category Two, a more intensive set of drugs, with more virulent side-effects, in 2010. With no improvement in test results, she was given Category Two drugs again in 2011, instead of being tested for drug resistance. "What can we do? There was no treatment for drug resistant TB available then," says Rano helplessly. The government program for the treatment of MDR TB was yet to begin. This repeated use of ineffective treatment possibly exacerbated Nurjahan's resistance.

She was still on Category Two drugs when a national laboratory was established in March 2013 in Kolkata. Her sputum sample was sent there for a drug sensitivity test. The sample came back positive, confirming she had MDR TB. By then, the government treatment program for MDR TB had also begun, and she was finally put on the correct treatment.

“I remembered that my child would be motherless if I stopped this treatment,” she says. “Who would care for her?”

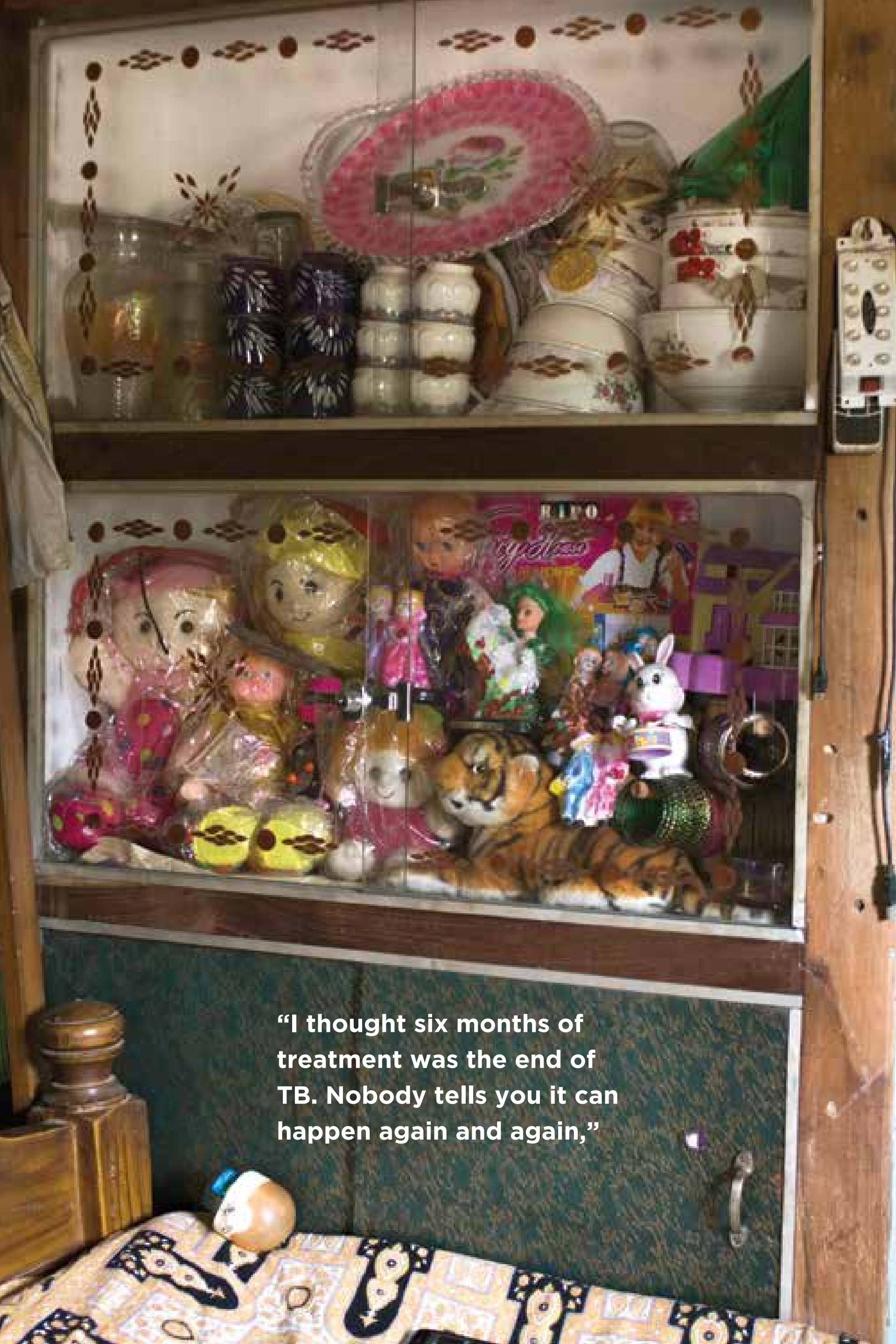
At some point in 2013, frustrated with taking these toxic drugs, Nurjahan gave up on the government treatment and went back to Dr Ali for an alternative treatment. Her counsellor managed to persuade her to come back.

Despite these multiple challenges, the misdiagnosis and 4 years of treatment, Nurjahan refused to give up. She had married her husband for the sake of her sister's daughter. She was determined to get well and be a good mother.

Her biggest fear was infecting Nargis, so for several months in her first year of treatment, Nargis stayed away from her in another room, being looked after by her mother-in-law. During the day, however, Nargis was permitted to be with her. Throughout her illness, Nurjahan's mother and took care of her. She moved into the house intermittently, sometimes for months, to take care of her and Nargis. "I would not have survived without her or my husband," Nurjahan says. TB-affected women in India fear discrimintion and separation from families the most.

The treatment for MDR was hard to tolerate. Nurjahan winces as she recalls that time. "Sometimes, my whole body would break into small rashes and my stomach would burn for months." There are still rashes over small areas on her face and body. Her kidneys, which were already weak, became worse with this treatment. Not surprisingly, Nurjahan often contemplated giving up, but the constant presence of Nargis stopped her. "I remembered that my child would be motherless if I stopped this treatment," she says. "Who would care for her?"

Initially, her husband panicked when Nurjahan was diagnosed with MDR TB. However, the doctors' counseling helped, and he understood that it was treatable. Due to MDR treatment, Nurjahan would be unable to get up and do anything for days. This can be a leading reason for women to be disregarded within families. At such times, her husband would take care of her and Nargis. "He would cook sometimes too," she says smiling.



"I thought six months of treatment was the end of TB. Nobody tells you it can happen again and again," The doctor advised her to improve her nutrition but money was limited. As a result, her husband, who is a tailor, moved to Bangalore to make more money. He comes back every few months, while Nurjahan lives with his family. “We couldn’t afford my food and her education with the work available here,” she says, gesturing gently towards Nargis.

Despite living in the same house, no one in her husband’s family helped her during her illness. They left it up to Nurjahan’s husband and her mother to look after and provide for her. Yet, they surround her as she recounts her story. “We live in the same house but have separate lives and kitchens,” she says quietly. “We all mind our business.” Even as she says this, her father-in-law interrupts her, assuring us that they are all nice to her. Nurjahan falls silent.

Nurjahan is excited that this is her last month of treatment. She asks her counsellor softly if she can become a mother after she completes her treatment. She wants to travel, send Nargis to a better school and bring her husband home. “I must bring him back and make my family whole again,” she says looking out of the window at a glorious orange sky announcing the end of day.

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DEEPTI

33, PATIENT ADVOCATE, MUMBAI

In the living room of her Mumbai home are photographs of Deepti, smiling broadly, with various Bollywood actors. She exudes confidence and strength– the ideal patient advocate for multi-drug resistant (MDR) TB tuberculosis, a disease so stigmatized and misunderstood that speaking out requires great courage.

“When I first wanted to speak [about my TB], many people advised me otherwise. They said, ‘It’s in your past, why do you have to tell anyone, you are well now and that’s what matters’. But I think for me it was that six years of treatment and two surgeries makes a very powerful story,” Deepti describes.

Deepti’s battle against TB certainly is a powerful story. It started seventeen years ago, when Deepti was a sixteen-year-old student preparing for her board exams. An X-ray confirmed that a persistent cough was actually TB, though doctors failed to diagnose her with MDR TB till many months later.

Deepti recounts her arduous years of treatment. "There's one drug, cycloserine, it makes you suicidal, it makes you irritable, and you just lose your mind. The family feels that the patient is doing this because he is not well and he's frustrated, but the thing is, he's doing it because he's on that medicine."

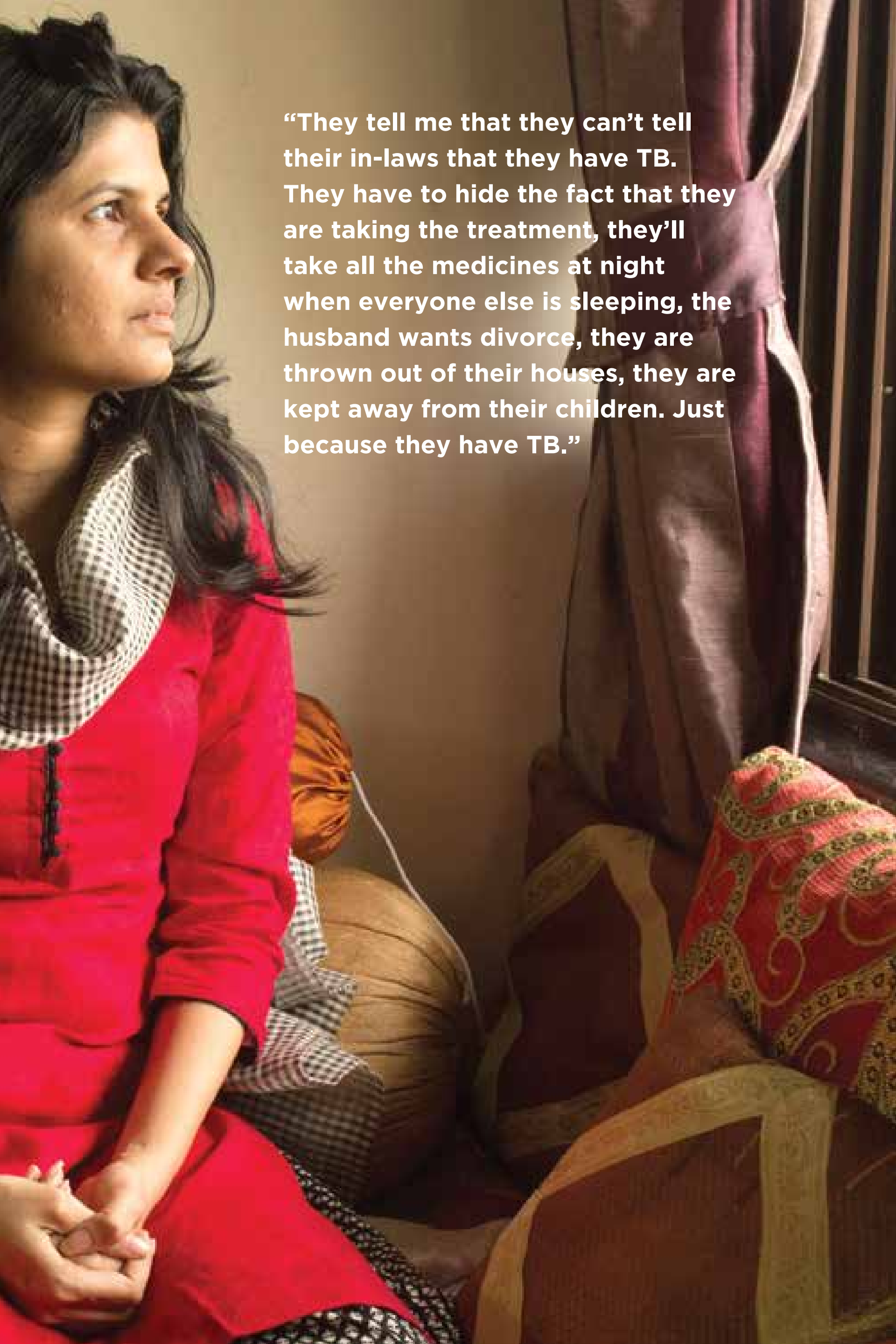
She continues, "There's another drug called clofazimine, which makes your complexion dark. It's a dye basically. I was afraid to look into a mirror. All your life you look a certain way, and you're used to that, so the drastic change in appearance, that did affect me."

In 2000, after Deepti's first surgery on her left lung, a common question her parents would get from people visiting was, "Now that she has undergone this surgery, who will marry her?" Deepti recalls thinking exasperatedly, at the age of seventeen, "Now that I am out of surgery, people should be happy that I am well, or maybe concerned about me, not asking who will marry me ten years from now."

Though her family was a huge sense of support, fighting for her despite doctors telling them to not waste their money and time, Deepti often didn't want to tell them about her fears. "Because even they were suffering," she says simply. Even when asked about her biggest concern now, Deepti speaks about not wanting to take a toll on her family, "If I'm suffering from anything which is not contagious, I can take it. I was lucky that no one else got infected at that time, but now I have that fear."

Deepti's completed her treatment in 2005. In 2011, Deepti married Neeraj, who she first became friends with in 2004, after meeting on an Internet chat site that provided a comfortable setting for Deepti to open up about her story. When Neeraj told Deepti he wanted to get married, her initial response was to say no because of her TB. But Neeraj was unconcerned, and ultimately his parents were supportive too.

Deepti first took on a public role as a patient advocate in 2014, with a radio interview. After that, she was featured on *Satyamev Jayate,* a popular television talk show by Bollywood actor Aamir Khan. She now



> “They tell me that they can’t tell their in-laws that they have TB. They have to hide the fact that they are taking the treatment, they’ll take all the medicines at night when everyone else is sleeping, the husband wants divorce, they are thrown out of their houses, they are kept away from their children. Just because they have TB.”

speaks regularly as a patient representative at a number of government events.

"I feel that there are lessons that everyone should learn from my story. Doctors because they misdiagnose, patients how they can cope up, everyone," Deepti says when asked why she chose to share her story, despite the dissuasion.

After her TV appearance, many patients began to ask Deepti for advice. The side effects of MDR treatment can be grueling, and few patients are properly informed about this. Now, Deepti is able to provide the counseling that she herself missed out on. The culture of silence that shrouds TB becomes more evident with every story Deepti shares.

"They [other patients] tell me that they can't tell their in-laws that they have TB. They have to hide the fact that they are taking the treatment, they'll take all the medicines at night when everyone else is sleeping, the husband wants divorce, they are thrown out of their houses, they are kept away from their children. Just because they have TB."

"I was fortunate that nothing of that sort happened," Deepti says, speaking of her gratitude in spite of her many years of suffering. "Right now I am focusing on being a patient advocate, because I don't think I can do anything besides TB. I can't treat patients, but I can support them in other ways."

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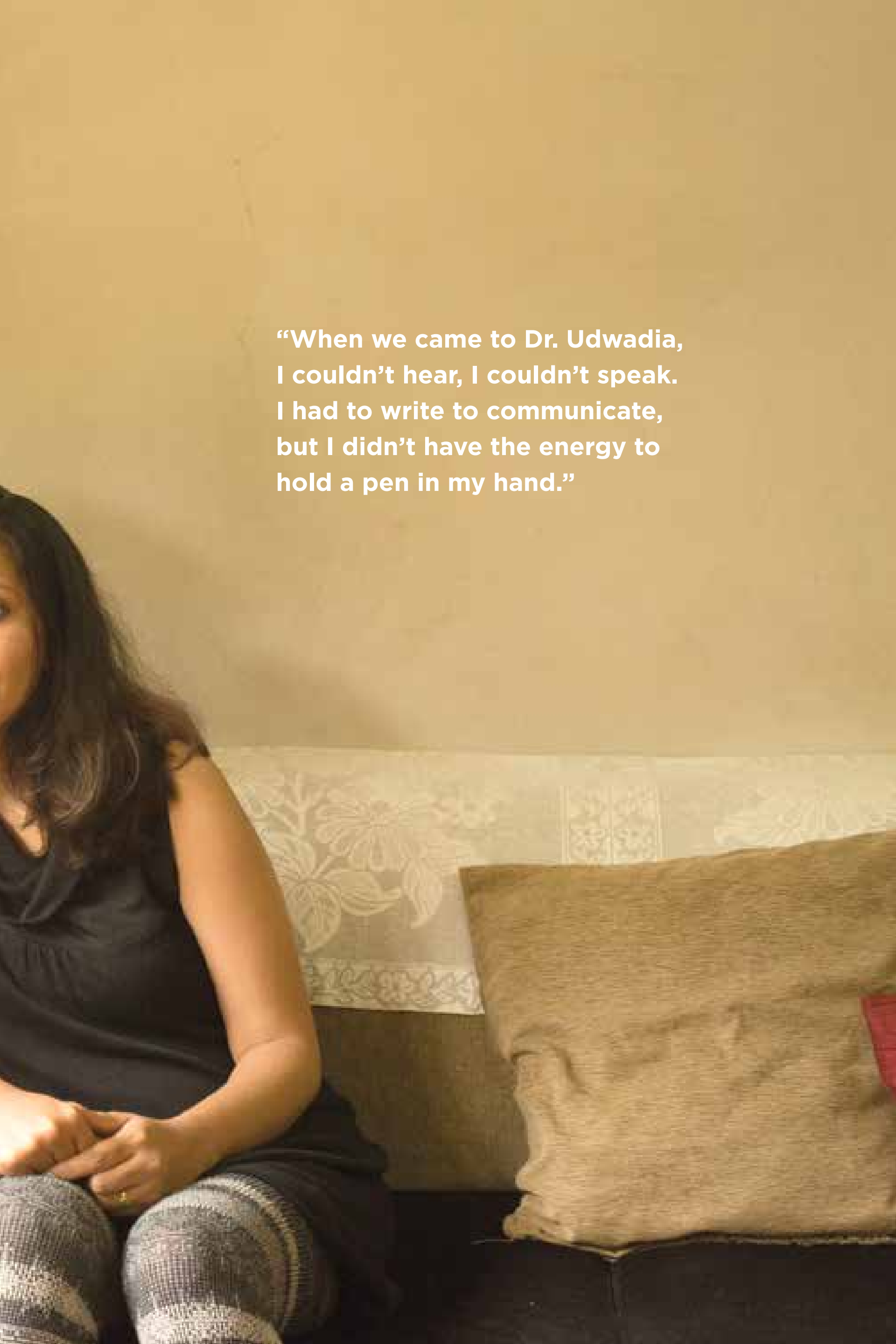
“Right now I am focusing on being a patient advocate, because I don’t think I can do anything besides TB. I can’t treat patients, but I can support them in other ways.”

DEBASHREE

28, ARCHITECT, PUNE

"Five years ago, I was at the peak of my life." Debashree sits in the living room of her home in Pune on a Sunday afternoon, surrounded by her family, as she thinks back to herself in 2011, a newly graduated architect, eager to move from Pune to Ahmedabad to start her first job. Debashree fell ill within a month and was diagnosed with multi-drug resistant (MDR) TB at the first test. She was resistant to three of the four drugs in the standard 4-drug kit prescribed, and her condition continued to worsen.

Within just six months, X-rays revealed the severity of the situation. The entirety of her left lung was destroyed, and the other lung was infected as well, which her doctor did nothing to try to save. "I used to vomit bowlfuls of blood, and the doctor used to just tell me, 'No, it happens.'" This was just the beginning of a series of oversights by doctors and



> “When we came to Dr. Udwadia, I couldn’t hear, I couldn’t speak. I had to write to communicate, but I didn’t have the energy to hold a pen in my hand.”

lab technicians; the people Debashree's family put their trust into. "You don't question a doctor, right?" Debashree reflects resignedly.

Lacking the strength to do anything, Debashree spent her days sleeping till late in the evening. Her grandmother helped her while her parents were at work. The physical toll the disease took on her body began to affect her mental health as well. "What happens is that you get so frustrated that you are in these four walls, you don't have the energy to look outside the window also, forget seeing another person. Within two to three months itself I had gone literally mad." The drugs also caused mood swings and affected her mental balance.

She was prescribed injections three times a day. These injections ultimately saved her, but were excruciatingly painful. Debashree had a nurse who helped care for her. "I used to cry, and Sister used to cry with me." Sister is present with the family this afternoon, and looks at Debashree fondly, reflecting on how brave Debashree was. It is clear that though she no longer works as Debashree's nurse, she remains a part of the family.

A dreaded side effect of the injections was a loss in speech and hearing, which made Debashree feel even more isolated. Her younger sister was the only one who managed to communicate with her, using sign language. "I used to take my sister with me when I used to meet my friends, and ask her to sign to me what they are saying, so that I can understand at least that much. It's just those small five minutes of human interaction that you need, especially when you're just sitting at home. For five years I've been at home."

Debashree also felt wracked with guilt and helplessness about things that were far out of her control. At her lowest point, she remembers thinking, "I don't mind dying, as long as they [my family] are put out of their misery of trying to find a solution to this problem." Because doctors failed to advise the family on how TB spreads at home, her younger sister also contracted the disease. A guilt-ridden Debashree describes the trauma of the discovery. However, because she was prescribed the right medication in time, her sister was able to make a remarkably speedy recovery.

As though Debashree's physical and mental fight against the illness and the side-effects of the medication was not difficult enough, she recounts the social stigmas that compounded her suffering. Blood infusions left her skin with an orange tinge, which people used to tease her about. "My friends did it as a joke, but it hurt. It's like you're becoming abnormal, the disease is changing you so much that you are losing out on even these small things."

Some of her friends avoided meeting her. Debashree recalls, "I told them, you wear masks and come, I'll wear a mask, no problem. But they said no. For them, it's easy to say, but for the patient who's already facing the disease, when your friends start behaving like that…" she trails off. So misguided are perceptions about TB, that there are still people who avoid her, even after she has fully recovered.

The insensitivity and ignorance of her extended family and others exasperated Debashree and her parents. She shakes her head as she recounts, "They used to say things like, 'Maybe she's not even a female anymore,' because my periods had stopped. I was on my death bed, right." People would frequently bring up questions about how Debashree would get married and have children. "Is it so important?" Debashree says with frustration. "She's fighting to stay alive, think of that first."

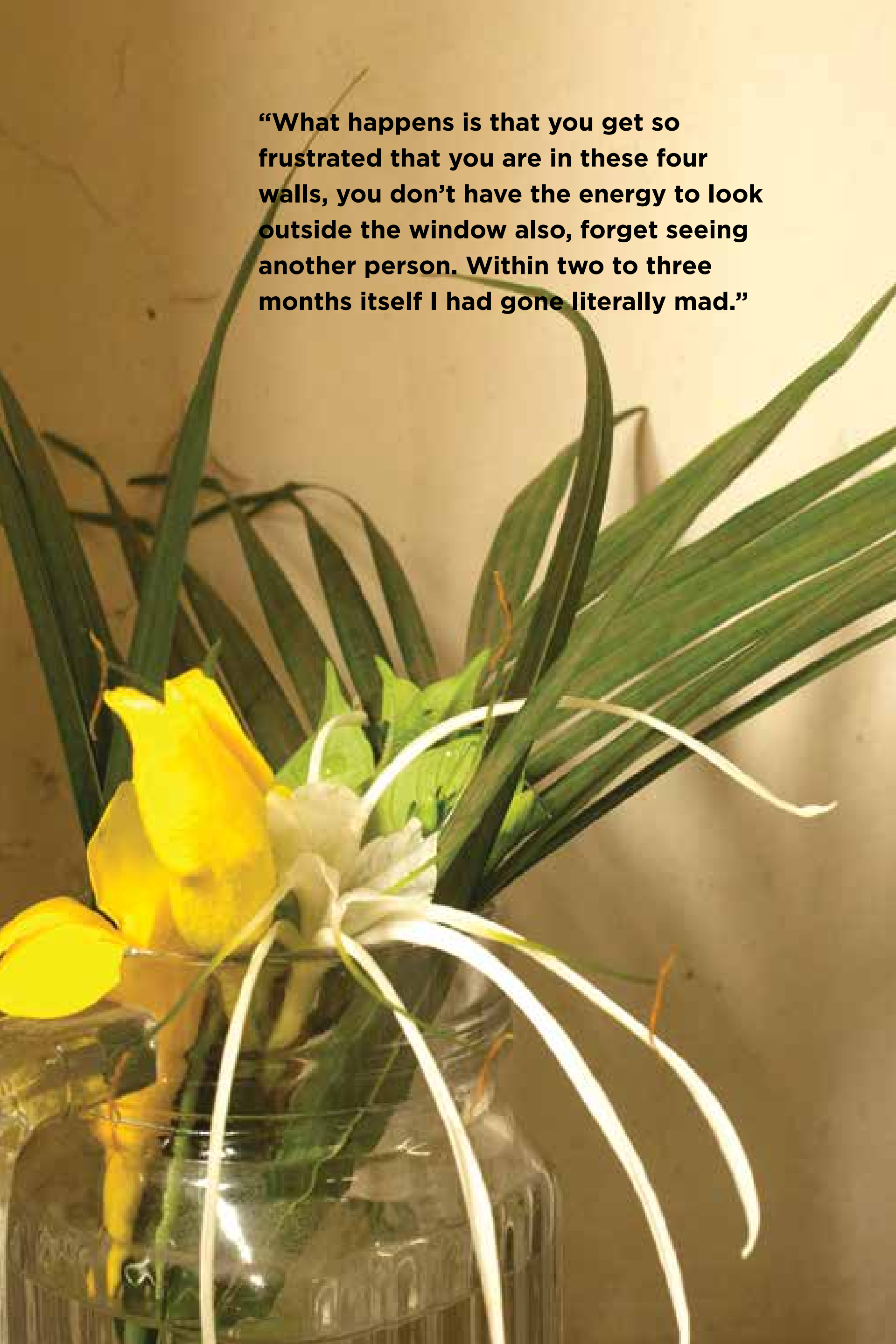
Thankfully, Debashree says her immediate family always assured her, "'Bahar ke log, they can say what they want, but at least we are with you, and we'll make you stand again.' And they did."

Though her parents did everything they could, their efforts were often misguided because uninformed doctors and incorrect lab reports led them in the wrong direction. Three years of medication, and Debashree only worsened. Her weight continued to drop, and at 28 kg her doctors in Pune wrote her off as a Totally Drug Resistant (TDR) TB case, saying there was nothing more that could be done. Debashree recalls Diwali of 2013, soon after an explosive report on TDR-TB in India was published. The usual festivities in the Lokhande household were replaced by a dismal air and the certainty that she was going to die.

Ready to put up one last fight, the family went to a doctor at Mumbai's Hinduja Hospital. "When we came to Dr. Udwadia, I couldn't hear, I couldn't speak. I had to write to communicate, but I didn't have the energy to hold a pen in my hand." Based on reports done at the Hinduja Hospital lab, she was prescribed a new set of medications, including the drug Bedaquiline, a new experimental drug which she managed to receive on compassionate grounds. Infused with a tiny bit of hope, Debashree said, "I stopped thinking, why did this have to happen to me, and started to focus on getting better." By June of 2014, after six months of intensive therapy, her sputum test eventually showed an improvement.

Today, Debashree has completely recovered, but those taxing three years still have an impact on her life, and on that of her family. Caring

> **"I used to take my sister with me when I used to meet my friends, and ask her to sign to me what they are saying, so that I can understand at least that much. It's just those small five minutes of human interaction that you need, especially when you're just sitting at home. For five years I've been at home."**



“What happens is that you get so frustrated that you are in these four walls, you don’t have the energy to look outside the window also, forget seeing another person. Within two to three months itself I had gone literally mad.”

for a daughter with TB, particularly paying for the cochlear implant that would correct her hearing loss, put a huge strain on the middle-class family. Debashree says her doctor failed to properly inform her about that side-effect, brushing it off as something that can be reversed later – a rather facile way of referring to a surgery that cost 25 lakh rupees. "My parents have had to give up their whole life savings for just my hearing," she remarks bitterly.

Debashree's mother adds, "We have two daughters. We have done everything for their studies, because we didn't know this thing would happen. Everything was planned properly – after 5 years, she'll finish her studies, she'll do her job for 1-2 years, and then she'll get married." Things were going according to plan in 2011. Her mother recounts proudly how Debashree graduated amongst the top of her class. "And after that, everything went in the wrong direction."

But things are finally looking up. Debashree can hear again, and she is able to work full-time now. She is also determined to share her story, so that people are more aware of the realities of the disease. "I am a big example of what a wrong report can do to a girl's life," she says, not with bitterness, but with hopefulness.

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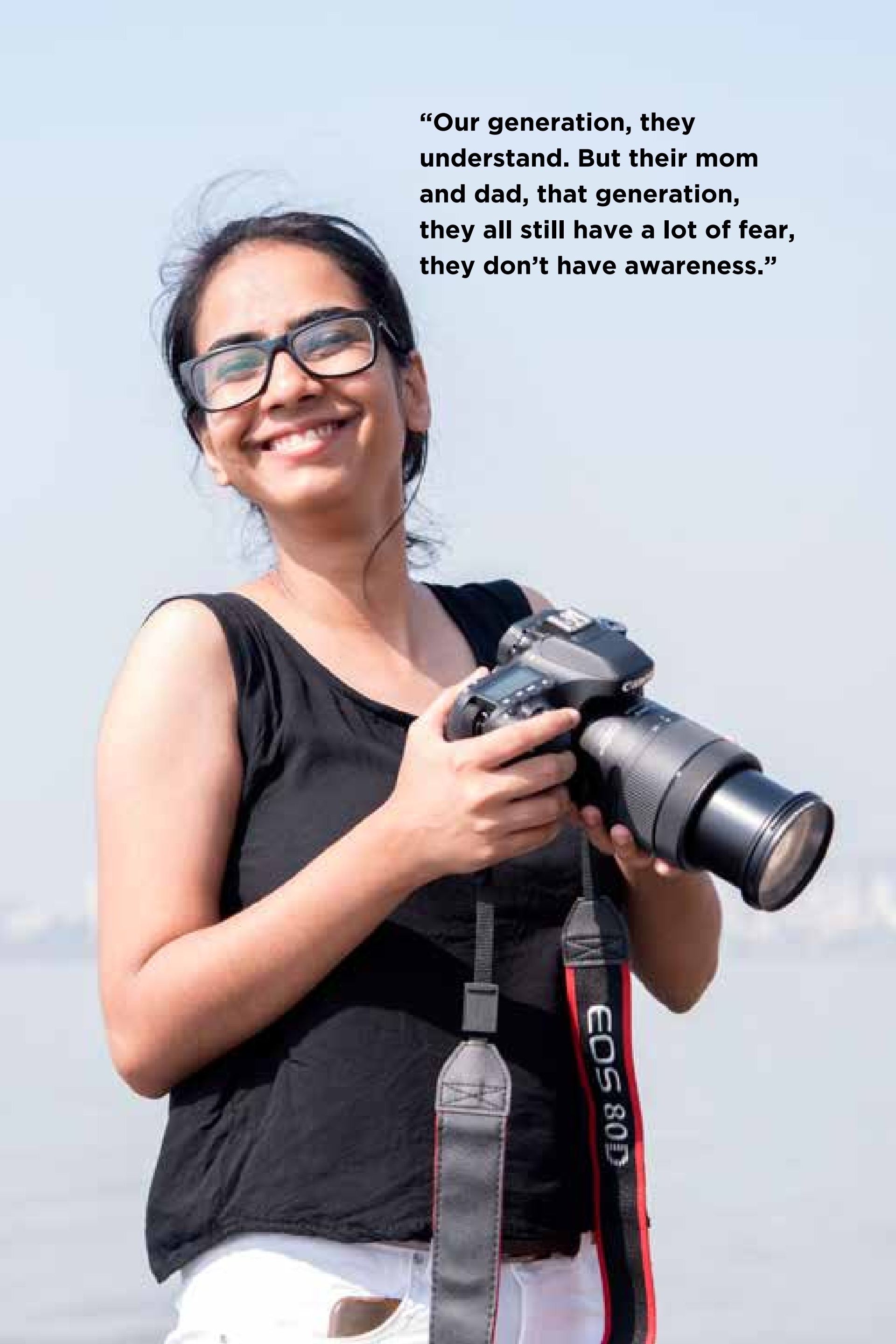
MANASI

22, PHOTOGRAPHER, MUMBAI

A student at Sir J. J. School of Art in Mumbai and a freelance commercial photographer, Manasi prefers being on the other side of the camera. She jokes about being uncomfortable when photographed, yet she displays nothing but confidence and vivacity. It's hard to believe that this petite young woman traveling around the city with a huge bag of camera equipment was bed-ridden just a few months ago.

Manasi was diagnosed in 2013, at the age of 19, when she began coughing and losing weight. Tests at the Hinduja Hospital in Mumbai, where Manasi has lived all her life, diagnosed her with extensively drug resistant XDR-TB. Manasi wasted no time in seeking the right treatment. "If I had gone to the government hospital I would have literally wasted six months." she says knowingly.



“Our generation, they understand. But their mom and dad, that generation, they all still have a lot of fear, they don’t have awareness.”

Besides for one drug that resulted in vomiting, Manasi was fortunate enough to not have any serious side effects. “Compared to other TB patients, I was doing really well.” She was also put on Bedaquiline a new drug for treating cases of extreme resistance for 6 months. She managed to survive it without any severe side affects. After a successful surgery removing a portion of her lung and six months of the right combination of drugs, Manasi started gaining weight again and began to return to her normal lifestyle. The biggest challenge of the treatment was a financial one. The family had to sell one of the rooms in their houses to fund the surgery.

This was not Manasi’s family’s first encounter with the dreaded disease. Manasi’s father, grandfather and uncles have also had TB in the past, and all have recovered. Manasi does not speak of this history with bitterness. Rather, her optimism shines through. She talks about how those experiences helped her know what to expect and how to deal with the disease, and also ensured that she was well supported. “You know how people say, ‘No, we won’t go to her house, she has TB.’ None

“If they understand, that’s fine, if they ignore me, that’s fine too. But without a mask, it can happen to other people too.”

of that happened with me." Manasi lives with her parents, her brother, and her brother's wife and their 9-month-old child. Her brother often put his job on hold so that he could be there for her in the year she spent at home recovering. Her close friends visited her frequently, even accompanying her to doctor's appointments.

Manasi witnessed people's lack of awareness about TB, and knows how damaging it can be. "For them, TB means, run far away and never see you again." While her friends behaved completely normally with her, their parents would warn them to stay away from Manasi. "My friends used to tell them, 'No, it's normal, it could happen to anyone, we have to take precautions.' Our generation, they understand. But their mom and dad, that generation, they all still have a lot of fear, they don't have awareness."

Besides for close family and friends, Manasi was advised against telling anyone else about her TB. No one in her extended family, not her neighbors, nor the people in her college, knew about Manasi's hardships. Manasi is unstintingly considerate, and talks about how she would have preferred telling people so that everyone could be careful.

Manasi was the patient, but the way she saw it, she wasn't the only one struggling. "My whole family went through it," she says. Seeing her mother cry when she dealt with Manasi's father's illness was extremely difficult for her. "I didn't want her to suffer this way for me," she recounts tearfully. When her father was being treated for TB, the psychological side effects of the drugs left him with depression and suicidal thoughts, particularly after Manasi was diagnosed. Manasi tried her best to control her own emotions for his sake. "If I also act like this in front of him, he will feel so bad. It's not about me. It's about him. I care about him the most," Manasi says emotionally. She was constantly cautious of overburdening her family, and underplayed her own struggles. She would talk about her illness in a light and humorous way. "TB hua yaar, bored ho gaya ek saal," she would say to her friends. "I used to take it as a joke, so that everyone wouldn't get too much tension."

Manasi describes herself as an athletic person, with a love for trekking and camping. She is bursting with energy, and as she rocks back and forth in her chair. It's easy to see that she must have found it difficult being bed-ridden for all those months. She recounts with a mischievous laugh how she started walking around the hospital when the nurses weren't around, with her pipes and bags of fluids, two days after her surgery. Three months after the surgery, she wanted to go with her brother on a trek. He said no, but Manasi was determined to try. "I did the whole camp and was completely fine. As we were trekking, every five minutes my brother would remind me, did you take your medicines?"

In August 2016, Manasi started going back to college and doing freelance photography jobs. Her life returned to normal- for the most part. A sense of fear still remains. "Even though I've recovered, there is a feeling that it will come again." Manasi describes how she forces herself to stay away from her baby niece, even though she has recovered. "I

don't go next to her only. If I do, it's just for a short while, and then I stay away." When she gets a cough, even if it's just a routine fever, she puts on a mask and makes sure that her whole family wears one too. Manasi eagerly shares her dream of going to Italy to get a Master of Fine Arts degree, but she worries that her medical history will prevent her. But as in all other aspects of her life, Manasi is persevering. "I am scared they won't want someone with XDR-TB. But still, I'll try. I want to go very far in this career, I will do my best."

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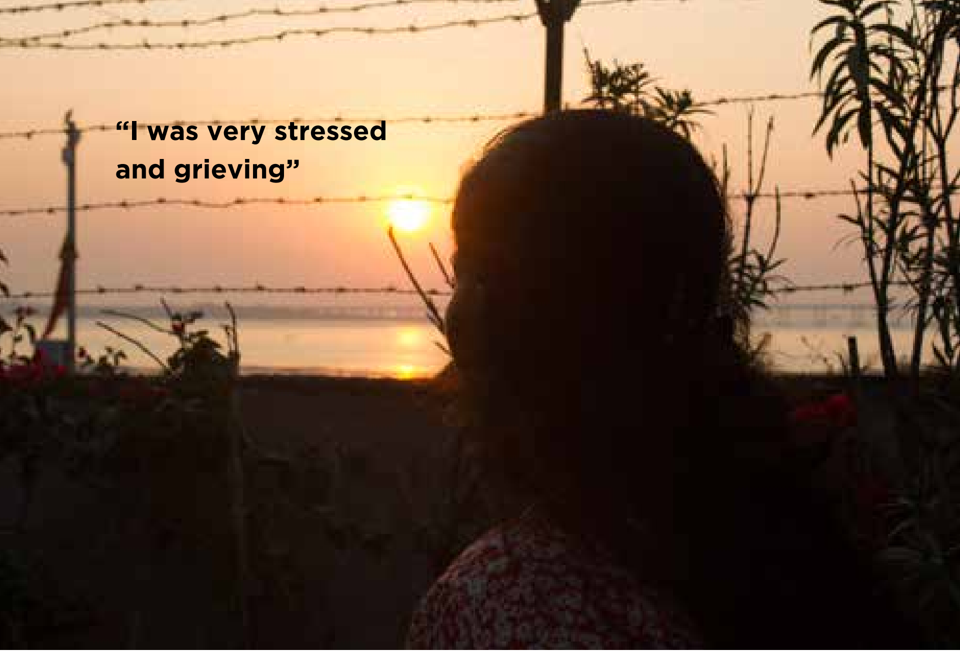


“I was very stressed and grieving”

SARIKA

32, CHARTERED ACCOUNTANT, MUMBAI

Sarika talks animatedly to her nephews aged 12 and 8 in the coffee shop. They are out with her this weekend. She laughs at something the younger one says touching his hair gently. It’s hard to imagine that just a year ago she was battling drug resistant TB with little hope for recovery.

Sarika was first infected with TB when she 18 and still in school. It was cough accompanied with high fever. She was treated for almost a year and it was cured. “I didn’t realise there was another time with TB” she says.

TB reappeared for Sarika soon after her brother’s passing. I was very stressed and grieving. I noticed that my monthly menstrual bleeding was very irregular and it was then I went to my gynaecologist. There was no diagnosis for TB though” she recalls.

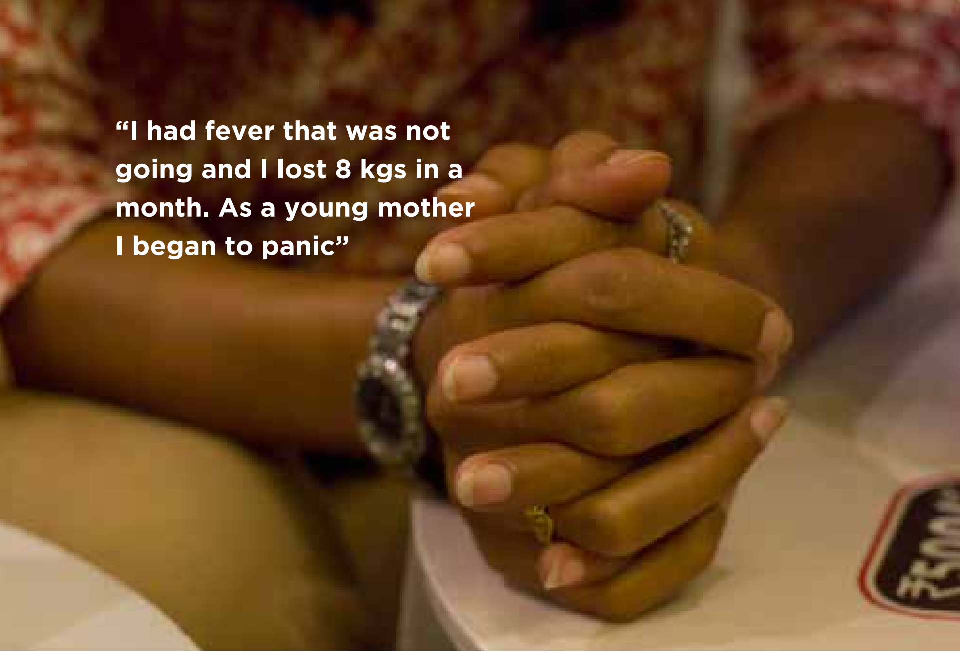
Numerous tests later her continuing poor health turned out to be TB. The moment Sarika realised it was TB she went back to her old doctor. "I had fever that was not going and I lost 8 kgs in a month. As a young mother I began to panic" she says. Her son was still very young.

Despite the treatment, she showed little improvement. "He still did not get me to do a resistance test. After a few weeks, I still hadn't gotten better so I decided to go to another doctor" she says. The new doctor got her to do her first sputum test on the molecular GeneXpert platform. The results left her stunned as the doctor explained to her that she may have gotten multi-drug resistant MDR TB. "The doctor told me that 10 patients die of MDR TB everyday at the TB hospital. Perhaps it was his way of scaring me but I completely panicked. He told me survival chances are not the highest which forced me to seek the best help possible. I had a young child and I was also responsible for my nephews. I had to get better" she says. Sarika's search brought her to Hinduja.

After several tests in February, 2015 Zarir Udwadia began Sarika on a revised treatment. It was his team that counselled and helped her through the process. "His assistant Shashank asked me everything from where I stayed to what I eat to how many windows my house had. I also realised that I should tell more people that I had TB. They changed my perspective entirely," as against she says.

Despite the correct treatment, taking the medicines was not easy. The side affects were hard to tolerate. "The moment I smelled food I would vomit. I began to hate the smell of food. There were also daily injectibles. I lost a lot of weight. The side affects were unbearable for months," as against she recalls wincing at the memory.

A charted accountant Sarika works for a large international consulting firm. She did not face discrimination at work and was able to tell her boss openly about TB. She got days off but had to eventually return to work. In between she had started working from home. The workplace was supportive yet the work pressure often made taking medicines



“I had fever that was not going and I lost 8 kgs in a month. As a young mother I began to panic”

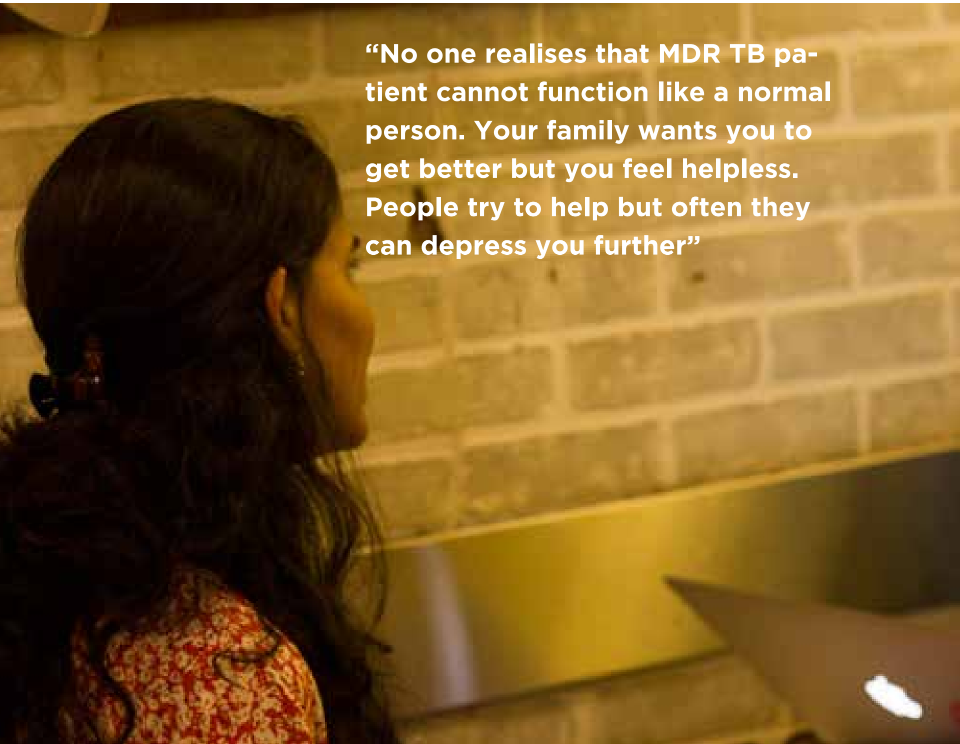
difficult. “You don’t want to act sick in front of your colleagues but you are. You can’t keep saying I have to leave early I have TB” she says. This was particularly challenging as she had to take intra muscular injections for several months. “Eventually I had to learn how to give the injection to myself as by the time I got home most hospitals would be closed” she recalls.

TB came with several economic stresses also. The couple had just bought a new house and Sarika’s inability to work for a few months and expensive medicines led to shortage of resources. TB was not covered by her insurance either. “It pinched us a lot and somewhere we realised we may have to sell our property. But I could not because I needed a separate room for myself to prevent others from getting infected. I eventually had to shift to our new house because it was more spacious and airy” she says. After her brother’s death, the families lived together. “They need me and I need them” she says looking gently at her nephews.

"We could afford the best treatment so we did. But it worries me because millions of Indians are affected by TB. So what happens everyday to them?"

For Sarika, the most difficult part was staying away for her son. “I didn’t touch my child for 6 months. I would see him everyday but then he was sent away” she says pained at the memory. She would sleep alone in a room for 5 months. “We had to teach him not to eat everything I had and not to come close. It was hard. How do you ask your child to stay away from you?” she wonders.

Her strength came from family particularly her husband. “None of this would have been possible without my husband. I would not have survived without his support. For three months he supervised my medicines. He faced problems with work also because his office told him that he was taking too many leaves,” she says, Sarika for her part felt extremely depressed and had to be put on anti-depression medicines. “You completely lack confidence that there will be life after TB. You feel you are trapped in it” she says shaking her head.



“No one realises that MDR TB patient cannot function like a normal person. Your family wants you to get better but you feel helpless. People try to help but often they can depress you further”

Her treatment was also troubled by stock outs of drugs, particularly a drug she was on which became entirely unavailable for a short period. Sarika didn't eat the medicine for a week and had to order the medicines online.

There was discrimination within the health system as well. She recalls with anger the behaviour that TB patients endure in hospitals. "Some hospitals don't even take TB patients because we are infectious. What happens if someone is dying of TB. What do you tell them that we can't admit you because we have centralised air conditioning ?" she wonders.

Reflecting on her battle against TB she says "No one realises that MDR TB patient cannot function like a normal person. Your family wants you to get better but you feel helpless. People try to help but often they can depress you further" she says.

According to her people with TB but without resources have few choices. "I never thought the government program would be as effective as the private sector. We could afford the best treatment so we did. But it worries me because millions of Indians are affected by TB. So what happens everyday to them?" she wonders.

"I did tell a few friends and family. I don't think they understood what MDR TB was. They all were supportive. But what TB patients really need is proper guidance and counselling. You also need to follow your doctor's advice. In the absence of information and reassurance you panic and make wrong decisions" she says.

Her nephews now restless look at her to end the conversation. They are ready for their evening adventure with their aunt. The family hails a kali peeli taxi to go to a suburban mall to spend the rest of the evening.

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TEJAL

26, DATA ENTRY OPERATOR, MUMBAI

It's still dark outside when Tejal and her mother started from their small home in Vadodra to undertake a 7 hour journey to Mumbai's Hinduja Hospital. It's for Tejal's quarterly meeting with her doctors who are monitoring her treatment of extremely drug resistant tuberculosis or XDR-TB. As the women reach Mumbai's crowded Dadar station they are joined by Sagar, a family friend. They have arrived a day earlier before the appointment so that they can rest and reach the hospital by seven in the morning. "There are huge queues and long waiting times," says Tejal's mother.

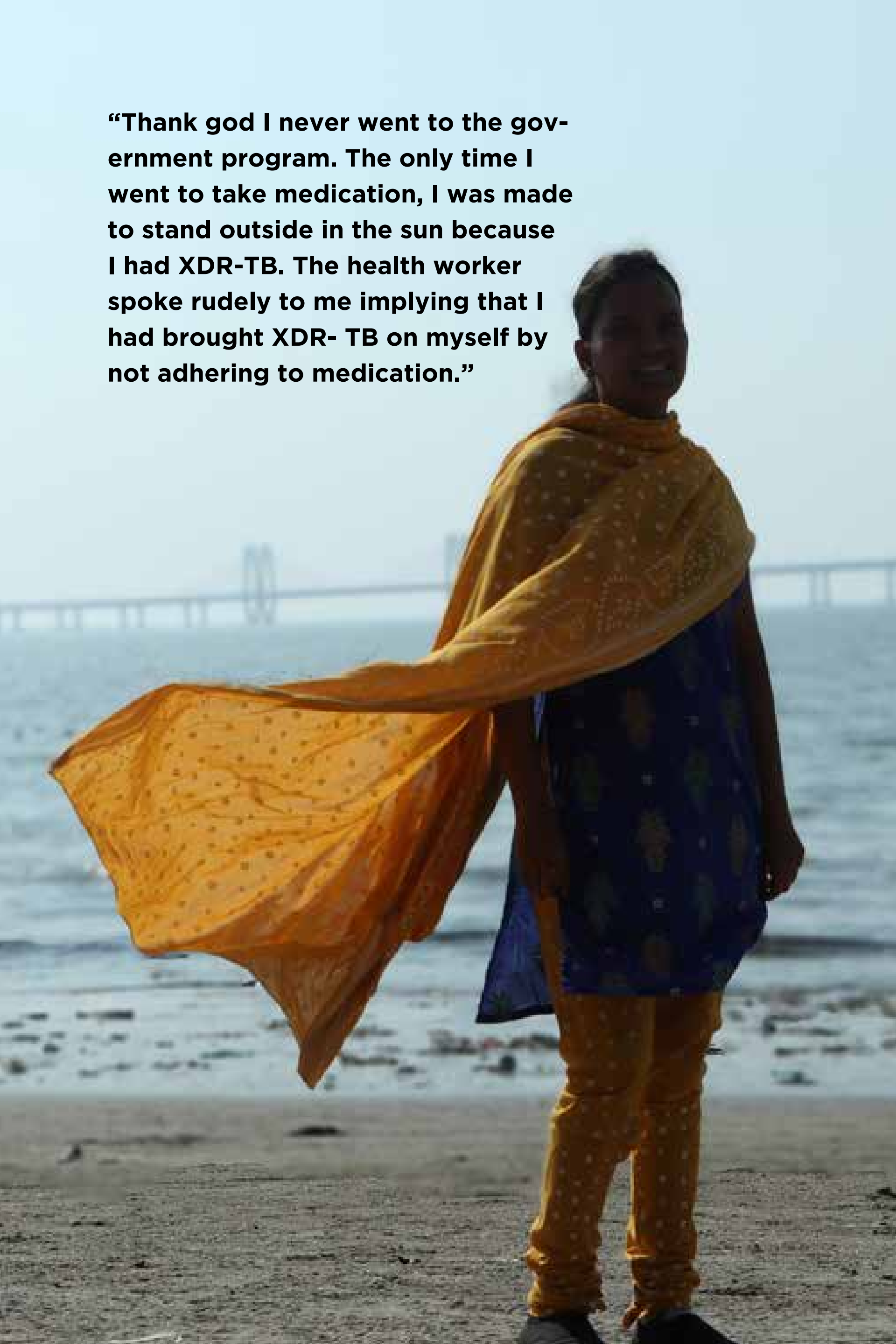
Tejal is upbeat and excited, she talks about the possibility of finally defeating TB- a disease she has been battling since 2012. "I was a counsellor at a computer institute when I started coughing. It was accompanied by fever and chills. I went to the doctor who diagnosed it as pneumonia and began my treatment", recalls Tejal. She took pneumonia medicines for one month and felt better but suddenly the cough and fever began spiralling out of control.

She developed breathing problems and had to be admitted to the hospital. The doctors still didn't test her for TB. It was her uncle who took Tejal to another doctor who ordered an X-ray which revealed her TB. Dr. Shah, her new doctor, took a look at her reports and immediately started her TB treatment. She soon began feeling better but could barely cope with the side affects. "I couldn't eat anything, could not sleep and my stomach was on fire", remembers Tejal. Neither the doctor explained to her about the side- affects nor did he tell her what kind of TB she had, forget testing for drug resistance.

Eventually, Shah told them that the case was beyond his capacity. Despite their best efforts, the family went from one doctor to another. Everyone turned them away saying that Tejal would not survive. She finally landed up in front of Dr. Dharmesh Patel one of Vadodra's most famous pulmonologists.

Patel looked at her test results and immediately sent her to Dr. Zarir Udwadia, India's most famous private sector TB specialist. In 2013, when Tejal went to Hinduja she got her first drug resistance test and was diagnosed with XDR-TB. With the tests revealing extreme resistance patterns, Udwadia chose to put her on Bedaquiline- a new drug- obtained with great difficulty through a compassionate use program. Tejal responded to Bedquiline well. "It wasn't as difficult a medicine to take. None of the side affects were extreme and I began to feel better". Her tests, 6 months later, revealed she was sputum negative for the first time in almost 2 years. For the first time, Tejal turned hopeful of a TB free future.

A few weeks later, falling weight led to some alarm among the doctors and new tests revealed that the bacteria had returned. She was put on more expensive drugs. These she could barely afford. "The costs were close to 30,000 and we barely had any income", her mother says. Due



“Thank god I never went to the government program. The only time I went to take medication, I was made to stand outside in the sun because I had XDR-TB. The health worker spoke rudely to me implying that I had brought XDR- TB on myself by not adhering to medication.”

to the illness she had given up working and her mother and sister were working to make ends meet and afford the treatment.

The costs of treatment were prohibitive. The family went under debt and borrowed from friends and relatives. Her elder sister had to stop her studies as a Chartered Account to fund Tejals' medication.

For Tejal and her family, help arrived from her doctors Dharmesh Patel in Vadodra and Zarir Udwadia in Mumbai. They didn't take fees from her for 3 years and have since been actively fundraising for her treatment. "The medicines are too expensive. Basically TB treatment is unaffordable for us. The costs make TB untreatable", Tejal's mother says quietly.

Tejal was ambitious before her illness. She was working as a Data Entry Operator before TB brought her life to a standstill. As the duration of treatment grew, it didn't allow her to work and she had to give up her job. This was because it made taking treatment on time difficult and she would often miss doses. "I would get delayed at work sometimes and it was not possible for me to tell people that I had TB." She constantly felt fatigued and barely weighed 40 kgs.

As the news of her sickness spread in her community, discrimination became rampant. Neighbours barely spoke to them and people would comment when she had the energy to go out. "If I reached a public space people would just leave. Or they would loudly say she has TB stay away, leave", she says. "Nobody realised I was non-infectious. There is so much ignorance about this disease that it makes life impossible for the TB patient", Tejal says remembering those days. A few would openly tell her that she is going to die her mother adds. However, this household of three women was resilient. "We had each other", Tejal says reassuringly.

There was no shortage of nay sayers. Many in her family suggested she should go for Ayurveda instead and stop going to the doctor altogether.

This suggestion was oft repeated when Tejal had to undergo a surgery. "When you are sick everyone has advice and no one has solutions", her mother says.

Post-surgery, while admitted in hospital, the hospital staff would openly discriminate against her. "I was moved from the first to the last ward as if I was an untouchable. Every nurse would request for me to be moved until Dr. Patel intervened", she remembers.

She had to take daily injections and eventually the cost of getting the injections from a health worker began proving expensive. So Tejal learnt how to inject herself through a port in her body. She has been doing so for almost 6 months, now. Another consequence of her long-term medication was a considerable loss in hearing. Even today Tejal strains to hear what is being said and often loses thread in conversations.

Tejal never went to the government program despite being unable to afford treatment in the private sector. It was impossible to navigate for her and her family with its long queues and endless waiting times.

More recently, a part of her XDR medication has been provided by the government while some she continues to buy due to differing approaches to treatment. “Thank god I never went to the government program. The only time I went to take medication, I was made to stand outside in the sun because I had XDR-TB. “The health worker spoke rudely to me implying that I had brought XDR-TB on myself by not adhering to medication”. What’s worse is that they once gave me expired medication”, recalls Tejal explaining her distrust of the public sector program.

Tejal continues to be resilient and hopeful. She has now been sputum negative for 6 months and has started looking for a job. She is hopeful that she will find one soon in the insurance sector and restart her life. Though open about her illness, she has to hide it now because her elder sister has to get married. “People are still so ignorant and petty. I have TB. How can it be such a big issue?”, she wonders.

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SAHER

26, BUSINESS PROFESSIONAL, NEW DELHI

When Saher was diagnosed with TB, she was neither frightened nor worried. “We are a family of resilient people. We are used to taking a problem by its horns and resolving it”, she says in a matter of fact way. Yet the journey of battling TB for her was filled with challenges, she had not anticipated.

Saher was abroad on a business trip when she began coughing. “Everyone says its nothing but I felt I was coughing my lungs out”, she says. Yet it never crossed her mind or anyone else’s that it could be TB. “It’s not like we don’t know about TB but it’s so far away from our thought process”, she says frankly.

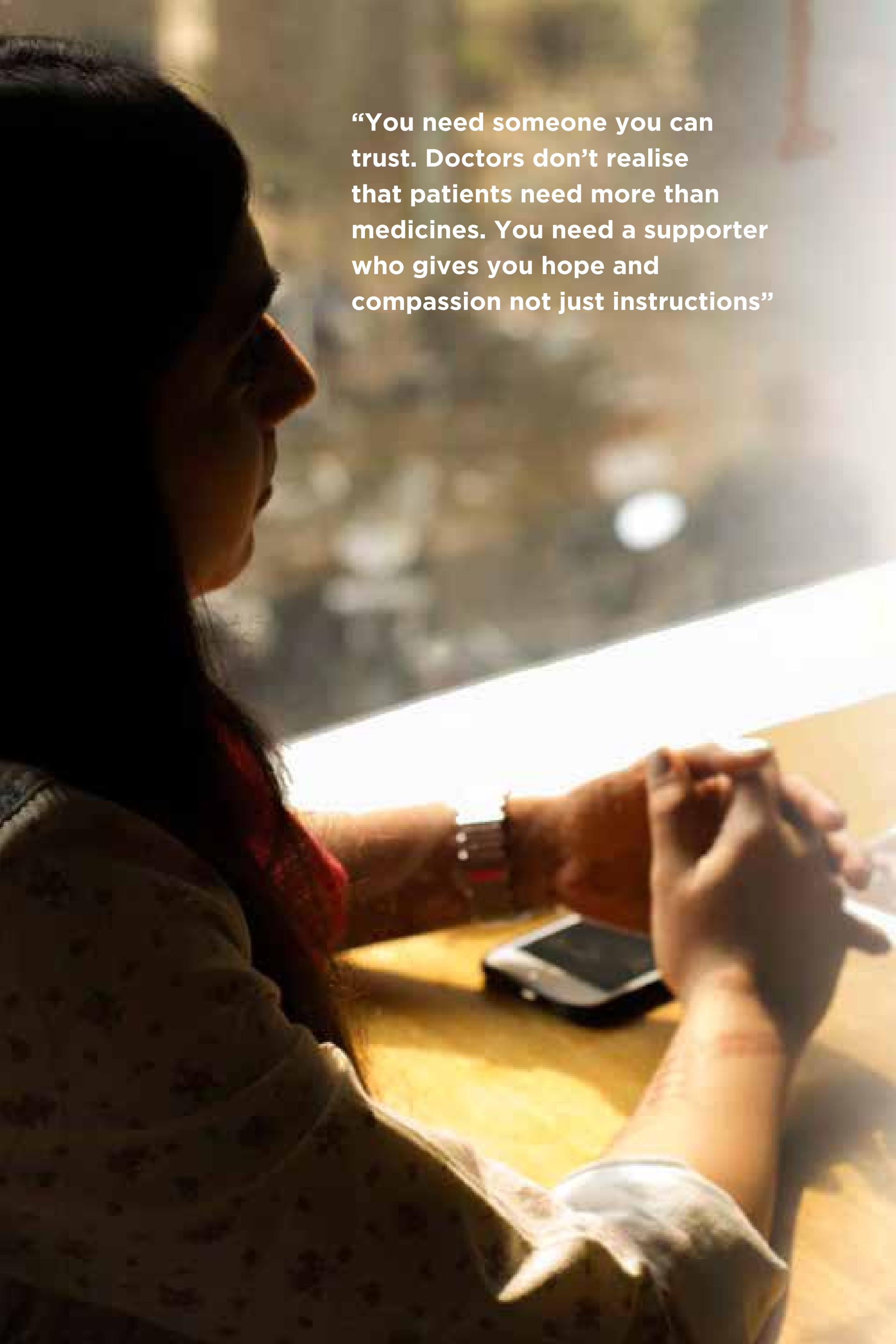
She came back to India and went to an Ear Nose Throat Specialist (ENT) who diagnosed her with hyper acidity. “Apparently I didn’t eat enough so I was coughing endlessly. I was given a lot of antacid and other medicines", she remembers. But the medicines had only marginal impact. Several weeks into treatment and she saw no significant change in her situation. The coughing became quite extreme and it became difficult to talk sometimes. Moreover, she felt exhausted all the time. "I felt like I had no energy at all. It was accompanied by escalating weight loss. Every day, I had to push myself to go to work", she remembers.

In desperation, she decided to change her ENT and was referred to one of the leading ENTs in the city. "We were so confused. No one could tell me what I had. He asked us to get tests done including an X -Ray and we got all those done", she recalls.

Saher and her mother went to see the ENT with Saher's reports. The doctor took one look at the X-Ray, walked to his cabin door and told them that he couldn't help them. "We could not believe it and reasoned with him to help us." He looked at them and said rather crudely "You have cox or TB", as if it was somehow their fault. "I could not believe that a doctor would behave like that" she says, angrily. The doctor immediately started speaking to Saher and her mother in Hindi somewhat condescendingly as if they were uneducated. "He advised us to leave and go to the government sector particularly the TB hospital in Mehrauli. It was then that we realised that TB was a disease associated with class. If you got TB you belong in the TB hospital", she says. Despite pleading with him he didn't really help much. At their insistence, he asked his assistant to give them the number of a doctor based in Delhi who could help them.

Saher had never felt more helpless. "I am usually the person, people turn to in the family but here I was with a disease I didn't know anything about and with no medical help available. How was I going to get better?", she remembers.

Saher went to the doctor immediately and he asked her to get a sputum test. Additionally he asked her to repeat all her tests. "It was criminally expensive. I felt like I was being taken for a ride. What happens to



“You need someone you can trust. Doctors don’t realise that patients need more than medicines. You need a supporter who gives you hope and compassion not just instructions”

those who can't afford it?" Saher wonders. Based on her test results, the doctor put her on treatment for drug sensitive TB. However, what Saher found frustrating was that the doctor treated her rather poorly. "It's frustrating when your doctor doesn't want to listen to you and you feel hopeless", she says. While family assured her that everything would be fine no solace was forthcoming from her doctor.

Saher with the help of her brother took to Googling and learning about TB. "I know it's wrong but WebMD for me was more reliable than my doctor. In the end instead of going to my doctor I would Google my symptoms and medicines first and then speak with him", she says.

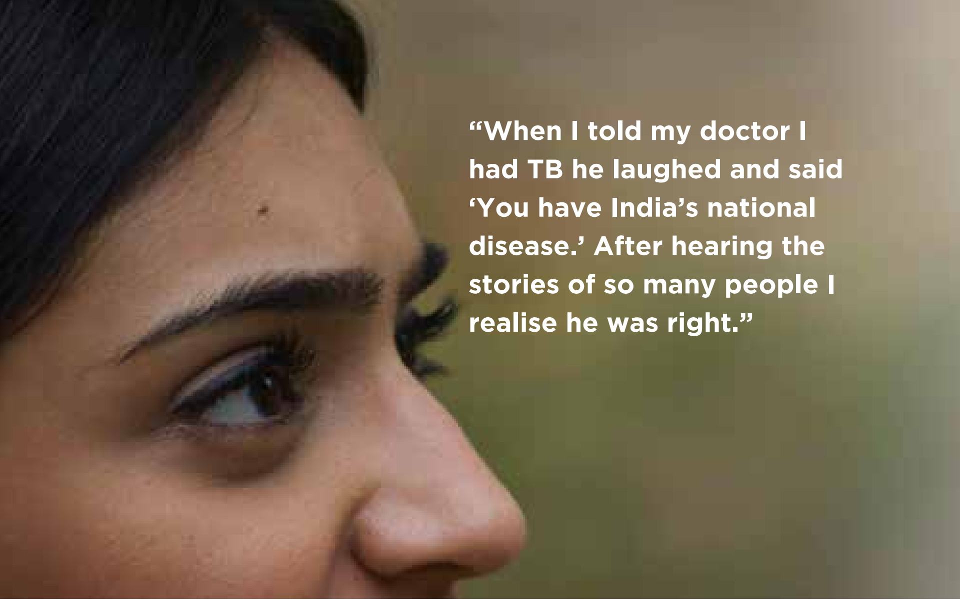
In the end she realised that this was not sustainable. In desperation, she went to see her pediatrician who had treated her illnesses from childhood. "You need someone you can trust. Doctors don't realise that patients need more than medicines. You need a supporter who gives you hope and compassion not just instructions", she says. Fighting TB suddenly became easier because Saher trusted her doctor. He was also associated with the Directly Observed Short Course Therapy (DOTS) program. “He explained everything about TB to me. I felt more confident of defeating TB”, she recalls. He also advised her on nutrition and side- affects.

Taking treatment was one thing but as time passed Saher realised TB would also have an impact on her professional life. Working in the corporate world with extensive travel meant she could not talk openly about her disease. She was also the only female member of a high-powered team where she chose to keep silent about her sickness. “When you are a woman in the corporate world you can’t show infirmities. You certainly don’t want to be the victim”, she says.

There was also the constant fear of infecting others. “My biggest fear was infecting someone in my family. Even though they assured me that it was fine. You feel terrified. I was always worried that my mother would be infected.” One of her friends was immuno-compromised and had spent a lot of time with Saher. Her concern was that she too might be infected. “I had read that TB is the biggest killer of HIV positive individuals and this really frightened me”, she says.

As time passed, she came to know more friends and family who had survived TB. “I realised no one talks about it but so many people I knew had survived TB. This silence feeds the stigma and misinformation”, she thinks. “When I told my doctor I had TB he laughed and said,’ you have India’s national disease.’ After hearing the stories of so many people I realised he was right”, she recalls.

After completing the treatment, Saher slowly brought life back to normal. Yet fears remain of a reinfection. “I was usually the strong one in the family but TB changed that. Every minor cough is scary”, she says. Saher continues to work as hard as she did before but TB has made



> “When I told my doctor I had TB he laughed and said ‘You have India’s national disease.’ After hearing the stories of so many people I realise he was right.”

her more health conscious. “Until TB, I took life and my health for granted but not anymore. I do everything to keep healthy and fight illness. TB has taught me that”, she says resolutely.

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HOW CAN

INDIA HELP ITS WOMEN FIGHT TB?

Overview: TB, like all other diseases, has a strong gender dimension that is often ignored within health systems and disease control efforts. This dimension is particularly relevant in India due to economic, social and cultural affects that impact women. While TB affects a larger number of men, vulnerability to TB has social and cultural dimensions that puts women at higher risk of suffering if infected. Similarly, ability to acccess diagnosis and care remains severly limited for women in India. The most significant of these risk factors remains a deep-rooted stigma that affects women more gravely in communities and families, leading to neglect and even abadonment. Hence, women suffer more severly when affected by TB.

Reccommendations

If India wishes to make its efforts at controlling TB more gender-friendly it would require several changes within the approach to disease control as also service delivery at the grassroots. This would include:

Counting The Women: While gender disaggregated data is collected within national surveys on TB, it is rarely dissemenated. The government must guarantee gender disaggregated data collection, its use, and dissemination. This data should be available in critical areas such as cure rates, progression to DR-TB and mortality.

This will ensure independent mechanisms at the country and state level to support, catalyse, and ensure accountability and progress for women affected by TB. Until this data is shared with all stakeholders, studied and analyzed our understanding of reasons for vulnerability of women will remain limited. We need to use this data effectively to target focussed interventions and expand services where needed to ensure that women get the services they need to address TB.

Gender Focussed Health Education: The government must design TB sensitization and awareness efforts specifically targeted at women in community settings with local advocates and ambassadors to complement service delivery. This will improve awareness, knowledge of available services and reduce stigma. Evidence shows that married women delay diagnosis and treatment because of fear of disclosure of the disease and desertion by husbands. In the long-term, this would have a transformative impact on the way women address TB at the individual level and within families and communities.

Stigma Reduction: A community's perception of TB determines the attitudes towards TB patients and also influences how easily patients seek care. Hence, taregted stigma reduction programs are essential for all TB affected. However, these programs especially benefit women as as they remain the worst sufferers due to stigma. Most women live in silence about their disease for fear of abandonment, difficulty with marriages, and social discrimination. Families and communities do not sufficiently understand TB and often have incorrect notions about TB affected women, leading to widespread discrimination. Hence stigma reduction helps create a supportive environment for TB affected women.

Counseling for Affected Women and Families: While counseling is essential for all TB affected, its need for women and their families is critical. Women often interrupt their treatment due to harrasement within families or their inability to continue in their roles as caretakers within families and communities. Families, in turn, often do not understand the needs of TB affected women and are not supportive. Here, comprehensive counseling and support throughout the treatment period for women and their next of kin can play a critical role in ensuring treatment completion and cure. For example, a gender-friendly adequately trained counsellor/confidante in all communities who can provide information and counselling on TB would be extremely helpful to women affected by TB.

Creating Improved Access to Diagnosis: India needs to invest and innovate to create community based models of diagnosis and treatment so that women can seek these services within safe and familiar spaces without the need to travel distances and incur travel costs. Women generally depend on their husbands/male family members to take them to a doctor as they are generally discouraged from going alone. Ensuring easy access will empower them to seek diagnosis with ease. Here community networks need to be tapped to ensure that diagnosis is early, free and accurate while maintaining confidentiality. Also improving quality of TB diagnosis and care overall will help reduce stigma, benefiting women in particular. For example, earlier diagnosis of extra-pulmonary TB would leave fewer women infertile, and more rapid initiation of effective therapy for pulmonary TB will rapidly reduce infectiousness.

Creating Improved Access to Treatment: Women affected by TB often fulfil dual roles of bread earners and caretakers within families. The government facilities have rigid timings which conflict with the women's own schedule. Additionally, social barriers along with travel costs inhibit women especially those with limited income and independence from continuing treatment. An alternative to this is making community and family DOTS available to all female TB affected wherever possible. This allows women to access treatment easily and conveniently.

Nutritional Support: Good nutrition has been shown to have a direct influence on recovery. Within Indian families, women often have poor nutrition due to discrimination and limited availability of nutritional foods (i.e., women are expected to put their needs last relative to other members of the family), Nutritional programs then are especially important for TB affected women who traditionally have poor access to nutritious food. They ensure food security and quicker recovery for TB affected women.

Economic Support: Apart from being caretakers, many women contribute heavily to the informal economy. Many own small businesses and as they become TB affected they need resources to support them during the treatment period. This will ensure that families do not fall into debt traps and poverty. It also ensures long term adherence and commitment to treatment completion. In the case of DOTS, the government should provide transport support as women have limited resources to travel to DOTs centres etc.

Integration of TB services in the Health System: Women need to be provided with TB information, diagnosis and treatment across the health system. This is because they have limited ability to finance and access health services, delaying diagnosis and treatment. Social and cultural factors often inhibit them from accessing health services. Concentrating TB screening and prevention/treatment interventions in places where women seek care for themselves or their children could reduce transmission. Hence, we need better integration of TB prevention,screening, and care into other aspects of health care system. Ideally, TB screening should be provided at health units providing services for maternal health, HIV, and other diseases. Maternal health programs are a good place to start because children and pregnant and lactating women are especially vulnerable to TB.

Conclusion: If India wishes to address TB comprehensively it must work to break the cycle of poor awareness, stigma and the inability to access diagnosis and treatment for women within the health system due to social and economic factors. Until these gender-sensitive policies are implemented, women affected by TB will be unable to fulfil their social, biological and occupational roles. By enacting these changes, we can ensure TB affected women are healthy, valued, enabled, and empowered citizens of India.

In the end, we must recognize that we cannot hope for social, economic, and environmental contributions from women in India unless they have the ability to address diseases like TB on their own terms and with dignity.

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